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June 1988

# Military Chaplains' Review

Spring 1988

## The Care Of HIV/AIDS Patients

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Professional Bulletin of the US Army Chaplain Corps

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# Military Chaplains' Review

Spring 1988

## The Care of HIV/AIDS Patients

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Professional Bulletin of the US Army Chaplain Corps

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**Peace**

**The Unit Ministry Team**

Persons interested in contributing an article on one of the themes listed above should coordinate with the editor to insure that the contribution fits well with other articles planned for the issue.

The *Military Chaplains' Review* prints an occasional "non-thematic" issue. Any subject having to do with chaplain ministry is appropriate for such issues.

**For AIDS patients and those who care for them . . .**

The final definition of individual or national character may well be drawn by the way we face death or by the way we care for those who die.

To deal with AIDS, and to care for those who suffer with it, is to deal with death—face to face—in its newest and perhaps most threatening guise.

In the past the *Military Chaplains' Review* has commonly dealt with issues of critical importance to our ministry for those in uniform. This issue is for those who suffer, for those who have died, and for those who care.

William Noble

Headquarters
Department of the Army
Washington, DC

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# Pastoral Care For Soldiers With HIV

**Mary A. Pitts**

Serving with units as diversified as the 1st Personnel Command and the 649th Engineer Battalion enables me to minister to a wide variety of people. My chapel sits directly between the battalion headquarters area and the USAREUR Band rehearsal hall; there are always people in and out.

One day, I glanced up from my desk to see Sp 4 Carr, a member of the chorus, standing silently in the doorway. Before I could say a word, he said, "Chaplain, I'm dying," and burst into tears. I brought him into my office, shut the door, and waited a few minutes for him to calm down. He told me that he had tested positive for AIDS and was already exhibiting symptoms. Although I had some general awareness of AIDS, this was my first counseling experience with an actual patient. It was made even more personal because I had worked with this soldier before and knew him fairly well.

The challenge of providing quality pastoral care to soldiers diagnosed as AIDS positive is three-fold: 1) support for the service member, 2) support for family members, and 3) support for the unit. How well we will be able to minister to soldiers facing this crisis will depend on two factors: our knowledge of the disease and its impact, and our integration of personal values with our theological backgrounds and beliefs.

Like most of the American public, chaplains are assailed with the mystery and confusion surrounding the disease. The biological and medical facts about AIDS sometimes seem to change overnight.

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Chaplain (Captain) Mary A. Pitts is a native of Ashboro, North Carolina. She did her undergraduate work at St. Andrew's College and holds the Master of Divinity Degree from Louisville Theological Seminary. Chaplain Pitts' ministry is endorsed by the Presbyterian Church, USA. Chaplain Pitts served in the 101st Air Assault Division, Fort Campbell, Kentucky; and she presently serves 1st PERSCOM and the 649th Engineer Batallion in Heidelberg, West Germany.

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Every chaplain should attend at least one of the training classes on AIDS now available at most posts, installations and military communities. Those of us serving outside CONUS need to understand the staging procedures and how the reassignment process works. We should note that family stress and trauma will be increased as social ostracism, isolation, fear, and sincere grief are experienced by the soldier and family members.

It is not only ignorance of the disease which will prevent ministry, but our individual responses. One of the goals of this article is to enable chaplains to look at him or herself, to examine his or her feelings honestly, and to determine if he or she is capable of working with AIDS patients. For a variety of reasons, not everyone will be comfortable providing counseling support to these soldiers.

The importance of this self-examination cannot be over-emphasized. A chaplain who is convinced that AIDS is a scourge from God, a punishment for a sinful lifestyle, and who consciously or unconsciously communicates this to the soldier is not going to be an effective counselor. It is better in such instances to refer the soldier to a chaplain who has had experience with AIDS patients. One of the problems facing line unit chaplains, however, is the very lack of experience that many chaplains have had in working with such patients. Though there have been some articles written concerning pastoral care to AIDS victims, and although Army regulations state that each soldier testing positive will be treated with dignity and respect, the whole area is so new and unknown that many of us find ourselves working from the ground up in trying to cope with the problem.

## Sin and Disease: The Biblical Background

The idea that physical disease is caused by a person's sin is an ancient one. In *Leviticus* 13:14 where the laws on leprosy are set forth, it is the task of the priest, the religious leader, to judge whether or not a person is diseased (i.e., "unclean" or healed ("clean"). In *John* 9:1,2 the disciples ask Jesus, " . . . who sinned, this man or his parents, that he was born blind?" Leprosy, which today is known to be a fungal disease treated with antibiotics, was a dreaded scourge in biblical times. There are even two instances in Holy Scripture where God uses leprosy as a punishment for a person's actions: *II Kings* 5:27 when Gehazi, Elijah's servant wrongly accepts a gift from Naaman, the Syrian general whom Elijah has cured of leprosy. Elijah then curses Gehazi with the disease, and not only is Gehazi punished, but his descendants are to be lepers as well. In *Numbers* 12 Miriam "murmurs" against Moses' authority and is afflicted. The horror of the disease is evidenced by Aaron's words to Moses on behalf of their sister: " . . . Let her not be like one of the living dead . . ." The fate of the disease was harsh, a life-long sentence. " . . . The leper who

hath the disease shall wear torn clothes and let his hair of his head hang loose, and he shall cover his upper lip and cry, 'Unclean, unclean'."

AIDS is thought by some to be the modern leprosy. It is looked upon by some as the punishment for a sinful, immoral lifestyle. In a sermon entitled, "The Bible and AIDS," Dr. James Kennedy, pastor of the Coral Ridge Presbyterian Church, Ft. Lauderdale, Florida, stated, "Down through all of the history of this world, God, in his long-suffering and patient kindness, has waited and urged men to repent and return unto him. But, finally the cup of his wrath has been filled to overflowing and he has on numerous occasions poured out his wrath on this country".[1] Kennedy further cites three biblical examples of plague as punishment. The great God sent a punishment for angels sleeping with the sons of men in *Genesis* 6:5 the destruction of Sodom and Gomorrah for homosexuality, and the plagues that God sent to Israel because of lust, idolatry and general sinfulness while still in the Sinai desert. Kennedy closes the sermon with an appeal for America to fast and pray to God to remove this plague from us. In this he is indeed following standard Biblical precedent. The Old Testament prophets urged the people to repent of their sins and even Jesus told his listeners on various occasions to "go and sin no more." Jesus tempered his counsel with mercy and forgiveness, something that many others seem reluctant to do.

## "What happens to me now that I have AIDS?

Much of the consternation among soldiers in Europe has been due to feelings of uncertainty regarding Army policy towards them once they are diagnosed as positive. According to the HTLV-III Screening Program—A Commander's guide dated August 1986, the following policy is in effect. "Soldiers testing positive will not remain in the theater. They will be processed through military personnel channels for return to CONUS after a medical evaluation. Commanders are admonished to ensure that those soldiers who test positive be treated with compassion and dignity and have the necessary support network." [2]

The Army screening program officially began 1 Aug 1986. Medical personnel arrange for mobile blood vans to come to each unit to draw blood. To ensure integrity of the samples, the vials are labeled in the soldier's presence with his or her social security number. In Europe, the samples are sent to the 10th Medical Lab in

[1] "The Bible and AIDS," a sermon by Dr. James Kennedy, Coral Ridge Presbyterian Church, Coral Ridge, Fla.

[2] Since the Commander's Guide was published, the AIDS virus has been renamed HIV. References to the Guide will use the original title, all other references will be HIV.

Landstuhl for the initial ELISA testing, then on to Walter Reed Army Medical Center for the Western Blot test. Two positive ELISAs and two Western Blot positives result in a diagnosis of positive for the soldier.[3]

The two basic reasons for returning AIDS positive soldiers to CONUS are the increased risk of infection from live-virus vaccines, and their inability to participate in battlefield blood donation programs. These soldiers are not deployable because they are at increased risk for infectious diseases. They must be sent where risk of infection is less and where medical treatment and support systems are available.

Once an initial Western Blot positive result is received, the physician calls the commander and requests that the commander accompany the soldier to the physician's office to discuss "a personal medical matter." The doctor discusses the ramifications of the test results with the soldier and the commander and both are contacted again should the second Western Blot be positive. Every effort is made to ensure confidentiality. Disclosure is limited to persons with a valid need to know.[4]

Does the chaplain need to know? The Army recognizes the right of confidentiality extended by a chaplain to a soldier in a counseling setting. However, the guidance set forth in the Commander's Guide does not state that the chaplain should automatically be notified when there is an AIDS-positive soldier in the unit. This notification will depend on the relationship between the commander and the chaplain, the perception that the soldiers in the unit have of the chaplain, and how well the chaplain is able to relate to a person with the disease.

## The Commanders Respond: Talk About Aids In The Unit

It is important for those chaplains in troop units to have some insight into how commanders feel about the disease. In the preparation of this article, I interviewed three commanders at company grade, field grade, and general officer levels. These three individuals do not speak for all commanders, but their responses give some sense of how they grapple with the problem.

The following questionnaire was used to interview the commanders. The company commander's response is indicated with a 1, the battalion commander with a 2, and the general officer with a 3.

Question: How did you first learn about the disease AIDS—TV, magazines, military classes or other?

[3] HTLV-III Screening Program—Commander's Guide, p. B-2.
[4] Ibid., p. C-3.

1. From TV. I watched a "60 Minutes" special about the disease a couple of years ago.

2. From magazines, news, and watching TV. At first, I thought the disease was limited to a small group of civilians. This was in early 1980, and I thought the disease was limited to homosexuals and Haitians.

3. From the media in the fall of 1981. I thought then that it might be bigger than we realized at the time.

Question: When you were first informed of the Army's educational/screening policy, how did you react?

1. When it became apparent that the disease was not restricted, I thought it was good.

2. By then, I had a greater desire to know more information. I thought the program would give more information on how the disease was transmitted, and I was right. For example, I didn't know that "innocent victims" could get the disease from blood transfusions, organ transplants or artificial inseminations.

3. I thought it was a well thought out program.

Question: What is your opinion of the Army's testing program of active duty soldiers, and what do you think of the treatment of the soldiers who test positive? Why or why not?

1. The benefit of course goes to the soldiers who test positive. We bend over backwards to help them, and I think it's unfair to those who test negative. However, since it is Army policy, I will give it my total support.

2. The intention is fair, I think it will prevent a soldier from infecting others. Statistically, I don't think we're following through in a practical manner to help get these people reassigned as fast as possible.

3. I think eventually that the coordination between the MEDDAC people and the personnel will change. Some of the current kinks will be worked out of the program. Our current program is as fair as we could make it with the information we now have.

Question: Should a soldier who tests positive for AIDS be retained on active duty until stage 4, or should the soldier be immediately discharged?

1. Enforce policy as it stands now and make life as good as possible.

2. This is my personal feeling, okay, but the Army is a 24-hr. a day organization and it is self-contained. I'm afraid that there will be much personal trauma placed on those that know about a person

in the unit who has AIDS, with regard to the fear of transmittal. In spite of the fact that we teach that it cannot be transmitted by casual contact, the average person has fears about this very thing. For instance, in a field situation for a long period of time, in cramped quarters, or in the case of a cook who tests positive, I think it would be demoralizing to the other soldiers in the unit if they knew they were living for long periods of time with a person who had tested positive.

3. I firmly believe that we should separate soldiers right away if they test positive. I distribute people. If I send 200 people somewhere and have 198 good ones and two that are unable to work because they are at stage 5 or 6 of the disease and are too ill to work, then I haven't fulfilled my mission requirements. Players who can't carry the ball are retired.

Question: How will you as a commander handle a soldier in your unit who tests positive?

1. We just send them on sick call to the hospital for three days, until they've had all the medical work and tests are complete. It stays between me, the soldier, and the doctor. The soldier remains in position until he or she makes a PCS. We provide as much support as the family or soldier needs.

2. They will continue to perform their mission. Again, the possible exception might be a cook. I just think that particular MOS could cause some uneasiness. The other MOS's would just stay in the unit until the PCS.

3. The soldier will be handled in accordance with Army policy, and this command will provide whatever resources and support we have to help the soldier and the family.

Question: What resources would you use to help the soldier or family members?

ALL: Medics, psychiatry, chaplain, commander.

Question: Suppose it became common knowledge in your unit that one or more of your soldiers had tested positive? How would you help the unit react?

1. Never confirm it. But if I felt the rumors were getting out of hand, or if other soldiers in the unit confronted me point blank about it, I'd reply that we are our brother's keeper, and we will treat this just as if the soldier had cancer or another terminal disease.

2. No discrimination—continue with a program of education. Again the cooks are the only MOS I'd feel compelled to do something about. Also, I'd let you know chaplain, so you could help defuse some of the emotion.

## Case Studies: Practical Ministry In A Troop Unit

In my counseling with AIDS patients, I have observed discernible patterns in each patient. The grief reactions and emotions, and the counseling issues involved are much the same. Three case studies are presented below, in verbatim form, with analyses at the end.[5]

### Case Study Number 1
### Mid-February 1986

The first case involves SP4 Carr, the chorus member described in the opening paragraph of this article. After he told me of his diagnosis, the following conversation ensued.

Joe: Chaplain, I went to tell MAJ M- (band commander) I had this. I know the doc will call him, but I wanted to tell him myself.

Chaplain: How did he take it?

Joe: He was just super! He's very supportive. He suggested I talk to you. I was planning to do that anyway. I know you and I have talked a lot, but I was a little bit afraid to tell you about this.

Chaplain: Why were you afraid?

Joe: Well, I just don't know how people will react. For example, I took my lab slip to have the blood drawn; and when the technician saw what it was for, she became hysterical. They had to get a nurse to draw it. It made me feel bad.

Chaplain: I can see why such an incident would upset you. How have the people in the unit reacted, or do they know

Joe: Yes, the chorus knows. They've been very good. It's just that unless you have this, you can't fully understand it. People have said "I'm sorry." (Angrily) I don't want people to say I'm sorry. I want a hug, or a touch, or something that indicates I'm still part of the human race. How would you feel if you knew that you were dying?

Chaplain: I'd be scared.

Joe: I am scared! Scared and mad. I can almost pinpoint the time when this happened. Even though I'm a Christian, I'm still afraid. This disease is terrible. It's a horrible way to die, and it's all my fault. I'm already exhibiting symptoms, look at my neck. (He turned his head to one side, and I could clearly see enlarged lymph nodes.) Why has God allowed this terrible dis-

[5] The case studies are true. All names and ranks have been changed for reasons of confidentiality.

ease to happen—not just to me—but to everyone that has it. Not all AIDS patients are gay, you know.

Chaplain: I don't believe God has "allowed" this to happen to you or anybody else. It's biologically a virus that is transmitted in definable ways, not as God's punishment. Joe, are you angry with God, or yourself or both?

Joe: Mainly myself for living the way I did. Chaplain, do you know anything about gay sexual habits?

Chaplain: No.

Joe: Many of us are or have been very promiscuous. When you get horny, you just go out and find someone—like running down to McDonalds for a hamburger. So you do it with hundreds of people in a year's time because you want something in your life to be fulfilling. And now, I'll never have a chance to do anything useful, because I've got two years max. My life is a loss.

Chaplain: Didn't you tell me one time you were from Wisconsin?

Joe: Yes, we have a dairy farm.

Chaplain: Do you enjoy farming?

Joe: (His face lights up) Yes, I love to garden. In fact I was hoping to go home in time to plant my trees. My mother has cherry and apple trees for me.

Chaplain: When you get home, why don't you plant those trees? They will provide beauty and fruit for many years. Perhaps even a little plaque on the first tree that states, "Planted by Joe Carr."

Joe: That is a thought. Then at least people would know I existed. Oh, I told my parents two days ago. They were very upset. My mom wanted to come over right away. They said I could come home though. It'll be good to die at home.

Chaplain: Would you like to talk about death now, or wait a bit? (By this time he had calmed down somewhat.)

Joe: No, now is fine. Aside from death, I wonder if I can handle the pain. I'm just so afraid of dying alone in some hospital room. I guess God won't give me anything I can't handle though. My grandmother died at our home. We took care of her until the end. I guess the loneliness of death frightens me more than anything: that and having no one to talk to . . . What can I do to keep from panicking over this . . . dying . . . I mean.

Chaplain: You're doing a good thing now by expressing your fears and feelings. You're right in your perception that

most people don't want to talk about death. It's an uncomfortable subject. I suggest when you get back, make contact with your state and county mental health association. Ask for information on two things: hospice organizations and AIDS support groups. Just being with people who have your problem can be helpful.

Joe: Whew (rubs his head) I've really dumped on you. Just one more thing. I need to tell my lover, and it's not going to be easy.

Chaplain: No, it won't be easy. He needs to know. If you want to bring him here and tell him, that's okay. Just tell him as gently and honestly as possible. Has he been tested yet?

Joe: No. I met him in a bar last year. Karl is German. He'll have to go to a German clinic.

Chaplain: Okay. I am here if you need someone. Would you like to have a word of prayer?

Joe: Yes, please.

Chaplain: (Takes Joe's hand and prays.) Lord, we lift our brother Joe up to you. Give him strength, help him to know that he is your much-loved child. Help him as he tells Karl about the AIDS. Most of all, give to Joe the assurance of the resurrection, the Good News, in Christ's name. Amen.

Joe: Thank you.

## Analysis and Commentary

My initial attempt to help consisted of just listening to SP4 Carr. He expressed his fear, shock and anger, as well as his disbelief. This was intensified because he had had a "conversion experience" earlier; and even though he was admittedly a homosexual, he had made a dramatic change in his lifestyle. Instead of multiple lovers, he had only one partner. Now he thought God was punishing him for all those years of promiscuity. He did not know if he had the emotional stamina to handle the physical aspects of the disease. He was afraid, since his AIDS was discovered during an ETS physical, that his parents would be burdened with medical expense.

Aside from the disease, the issue of death at age 26 was preoccupying for him. He told me that he felt he had lived a useless life and would die without accomplishing anything. Nobody, he said, would talk to him about death, only about the physical symptoms that would lead to death. He felt guilt, too, over his lover who did not yet know of the diagnosis. SP4 Carr was unsure of how to tell him.

The main concern seemed to be the threat of dying in an isolated setting. I felt that the best way I could help SP4 Carr would be to let him vent his emotion until he could talk more rationally. He cried, off and on, throughout the whole conversation, though not as hard as he had for the first few minutes. I didn't try initially to take his guilt away from him, because I believe that a human being in crisis must express guilt before moving on to reconciliation and forgiveness. He exhibited the emotions of many terminally ill patients: anger, guilt, frustrations, with not much "why me" because in this instance he knew why, and not much bargaining, I think, because of his religious faith. I did not say very much in this session because I thought he needed to do the talking. I did try to get him to focus his feelings—i.e., anger at himself or God.

I suggested the hospice and AIDS support groups so that he could receive some emotional support later. Organizations are also good sources of support for family members. By asking about the trees, I hoped to give him an idea for something that he could do that would be useful and endure beyond his own life. Finally, by showing him I was not afraid to take his hand for prayer, I hoped to indicate to him that he was still a valuable human being. In the midst of such horrible and devastating disease, the worse thing we can do is treat someone like a pariah. The best we can do, in Paul's words, is to show a person that nothing, not even AIDS, separates us from the love of God in Christ Jesus.

He made an appointment for three days later, and during the month and a half before he left for the states, I saw him twice weekly. Mainly I served as a sounding board, but over the counseling sessions we discussed:

1. Forgiveness, hope of the afterlife.
2. Mood swings—ups and downs.
3. Sense of isolation and separation.
4. Changes in his physical condition; his fear of death intensified every time he had a cough or a headache.
5. His background—what he perceived to be the reasons for his homosexuality.
6. His feelings of being unworthy and unloved.
7. How he would relate to his family when he returned home.

## Case Study Number 2
## March 1986

The second case involved a 27 year old E-6 assigned to my unit as a computer programmer. SGT Bower was, at the time of his diagnosis, married. His wife was 25 years old. He telephoned my office early one morning asking for an appointment. I told him to come over in

about an hour, if he could get away. He showed up, sat down, and began to talk.

SGT Bower: Well, I'm here because I have some bad news. I just found out. I am positive for AIDS! I just can't believe it!

Chaplain: That's pretty devastating news. How did you come to be tested?

SGT Bower: One of my friends is positive, and he urged me to go get tested, so I did. You won't mention this to anytone will you chaplain?[6]

Chaplain: No, absolutely not. Anything you tell me stays here unless you tell me you're going to shoot me or kill someone. Then I'd have to do something.

SGT Bower: (laughing) No. No, nothing like that. I guess I'm still stunned by the news. I've got to figure out how to tell my wife. With all the other problems, this won't help.[7] What do you think I should do?

Chaplain: Well, you'll obviously have to tell Marian, but first maybe we should talk so you can sort some of your feelings out. I'll help you as much as I can.

SGT Bower: I know, I guess that's why I'm here. You know I still can't believe this. Maybe I just took the test when I had a cold, or maybe the results are false. Not really, though, both Western Blots were positive.

Chaplain: Yes, that's definitive. Can you talk about your feelings, or maybe what led to this?

SGT Bower: You know my home life chaplain. After Marian and I got married, we did the swap act for a year or so. I've been out to the gay bars, since we've been here, but I'm not queer. I have had some bisexual relationships, especially the last six months. I did it with the wrong person. I was treated for clap, but when my friend came up positive, he said I should be checked too. My parents will die!

Chaplain: Have you told them yet?

[6] The official Army testing program did not begin in Europe until August 1986. Testing was available on an individual basis through the hospital.

[7] I had been counseling SGT Bower and his wife for marital problems for the past nine months.

SGT Bower: No, I think my mother will be supportive, she's a volunteer in an AIDS clinic, but my father won't understand. I'll have to go home though. I have nowhere else to go. (He starts to cry, gets up and paces the office.) What did I do to deserve this? What if my family rejects me? My father has never loved me anyway, nothing I could do ever pleased him, and chaplain, I don't want to die! I want to live, have a family, enjoy life. Now I can't. (He continues to cry for a few minutes. I said nothing, but handed some tissues.)

Chaplain: What scares you most about this?

SGT Bower: Well, death itself. Anybody would be, cancer patient or whatever. But for now, I'm afraid to tell Marian and my folks. My wife will probably divorce me, and I'm afraid my parents will abandon me. I'm afraid I'll end up sick and alone, with no one, like the man in the New York City hotel, where they would leave his food outside the door. He was too sick to get to it.

Chaplain: You're close to your mother, and she works in an AIDS Clinic. Have you thought about breaking the news to her first and letting her decide how to tell your father?

SGT Bower: Yes, I'll do it that way. I was thinking along those lines anyway. My wife will have to be tested, too. I think I'll just try to tell her as calmly as possible. We've used condoms regularly, so maybe she's not infected. I'm sorry I lost control awhile ago.

Chaplain: It's all right to cry.

SGT Bower: Chaplain, the other thing I'm scared of is physical pain. I mean I have a low pain tolerance—it's a major effort for me to get a shot. I'm thinking seriously of asking for medication towards the end if it's bad so that I can go ahead and die. Do you think I'd be wrong? I was always taught suicide was a sin, but Jesus, if I'm going to die, I want to suffer as little as possible.

Chaplain: That's a decision you'll have to make when the time comes. It's a valid feeling. If you're asking me if I think God will condemn you ifyou choose that route, I don't. I urge you

when you get home to seek out a hospice group, an AIDS support group, and to talk with your priest. Get support from as many areas as you can.

SGT Bower: I will. Look, if Marian wants to come and talk, is that okay? She's Catholic and I'm Episcopal, but that's not a problem, is it?

Chaplain: No, you're both welcome, and if she'd prefer a priest, I'll refer her to one.

SGT Bower: Thanks, Chaplain, I'll be back in next week. Can we set an appointment?

Chaplain: Yes. Before we do, would you like to pray together?

SGT Bower: Not now. I'm just not in a praying mood. You're not mad, are you?

Chaplain: At some point, when you feel more comfortable, we will.

SGT Bower: Thanks again.

## Analysis and Commentary

The initial concern of SGT Bower was confidentiality. He needed reassurance that his problems would not be talked about. Most people with a positive diagnosis are sensitive on this point. In one response he refers to "other problems." This couple had had on-going marital problems for a year. Notice that SGT Bower directly asks the chaplain for advice.

The denial that SGT Bower exhibits is common among AIDS patients just as it is with any person who has received notice of a terminal illness. Part of SGT Bower's concern was fear of death and anger at the situation. He felt he had never lived up to his father's expectations, although he was close to his mother. The feelings of loss, grief, isolation and abandonment expressed are too often a reality; many times family members reject the person with AIDS.

When the issues of how much physical pain can be tolerated and the right to die with dignity came up, I expressed my opinion on the subject, but gave responsibility back to SGT Bower by stating that he'd eventually have to make a decision. If no cure for AIDS is found, the question of how long to sustain a painful, debilitating life will become more urgent. Chaplains will need to have a clear understanding of the ethics involved in such decision making. Chaplains may be called upon to assist medical staff as well as family members and patients with this issue.

## Case Study Number 3
## Early April 1987

One afternoon as I was walking through the motor pool, the first sergeant drew me aside. He wanted me to see one of the NCOs who had just found out that her husband was positive for AIDS. I talked with her the next day.

SGT Noel: I'm so mad! First the hospital called at 7:30 AM yesterday to tell me John was in the hospital and for me to come ASAP, but they would not tell me why. They called back about fifteen minutes later and said to come at 1100. I sat there the whole morning wondering what was wrong. I guess Top told you, didn't he?

Chaplain: Yes, but only me. He felt you needed to talk to someone outside the unit.

SGT Noel: Yes, I do. This is awful, I knew he had other women, he did before we got married, but AIDS . . . how could he get AIDS? He's not queer, and he doesn't do drugs. I just don't know what to do. (She begins to cry.) Maybe if we weren't apart so much, this wouldn't have happened.

Chaplain: How long have you known about the other women?

SGT Noel: For a long time. We dated four years, and I knew he had other women. I was mad, but he said it was just part of a man's nature and that he loved only me. This past month his unit has been in the field. I just don't see how he's had time. I'm mad now, chaplain, but I was madder when I talked to the social worker and asked her what I should tell people in the unit. She said to tell them that he had gonorrhea. Why should I do that? That's admitting to everyone that he screwed around, or I screwed around or both. I don't want the whole unit talking. What am I going to tell people, chaplain?

Chaplain: Why do you have to tell them anything? If anyone asks, just say that your husband is in for tests. People go in and out of the hospital all the time for tests. It's no one's business but yours, SGT Noel. You're not required to give an explanation to anyone unless you choose to do so.

SGT Noel: That's true. I haven't told the CO either. Do I have to tell him? I don't trust him.

Chaplain: Top knows and I know. Since your husband's chain is aware of the problem, I don't think it would hurt for you to wait a bit. If you decide to go back to the states with your husband that's time enough to tell CPT Lionel.

SGT Noel: Yes, if I'm positive, the hospital will call the battalion commander. Maybe I should tell him. Could you talk to him, Chaplain? He won't tell CPT Lionel would he?

Chaplain: No, I don't think so. Why don't you think about it for a day or so then let me know. I'll talk to the LTC if you like, but you think about it first. I won't do it without your permission.

SGT Noel: That's fine. I'm not thinking straight today. All anyone has to do is look at me wrong, and I cry. I just hope I can get through this. I had an AIDS test today, too—it will be ten days before the results are in. Thank God for the ARTEP. I'll be too busy to think, I hope. Chaplain Pitts, will you please pray for John and me now?

Chaplain: Yes. (Takes SGT. Noel's hand.) God, we lift our sister and her husband up to you. Help them in this time of need. Let them know that you are in their lives to comfort, heal and give hope. Your love and care surround them, and they are not alone. Let them know there are people who care. Give them your strength, in Christ's name we pray, Amen.

SGT Noel: I'll see you in the field, Chaplain, thanks.

## Analysis and Commentary

An issue that surfaced in the session with SGT Noel is that of appropriate notification procedures. This incident was handled poorly by the hospital. Most hospitals will not give out medical information on the phone. SGT Noel expressed her anger at the way she was notified. Because her husband had had extra-marital affairs, she experienced feelings of guilt and betrayal, but blamed herself for not being able to change him.

Soldiers who are in small units also feel a desire to give people explanations. The advice from the social worker was poor and contributed to the feelings of anger and betrayal.

A lack of trust in the chain of command is also indicated in the narrative. Although both husband and wife were service members, only the chain of command of the AIDS positive member was notified. SGT Noel's husband was assigned to a unit in a different command located about 55 miles away. He came home on weekends when he wasn't in the field. It was left to the spouse to decide how much or how little she wanted to share with the chain.

A day or so after this session, SGT Noel returned, asking me to inform the battalion commander of the situation and to leave it at that until her test results returned.

A positive diagnosis results in much stress, anxiety and confusion for family members. SGT Noel was able to continue to function by keeping busy through the ARTEP and by receiving support from the battalion commander, the first sergeant, the chaplain and one close friend.

NOTE: SGT Noel's AIDS test was negative.

## Practical Ministry: Where Do We Go From Here?

I wrote in the opening paragraph of this article of my first experience with an AIDS patient; it occurred in February of 1986. Since that time, I've counseled with two dozen or more who were either AIDS-positive or who were concerned that they were at risk for the disease. Some have come from my units and some have been referred.

Several of the counselees who thought they had been exposed and were waiting for test results to come in experienced high levels of stress, anxiety, anger and guilt. Practical ministry here means being able to listen to an endless litany of "What if? What will I do if I have AIDS?" It requires the chaplain to help the person focus on lifestyle patterns so that he or she can think about behavioral changes. This may include celibacy, safer sex, no promiscuity, or drug therapy. This counseling must be done without condemnation. It must express care for the person, but stress the need for a change in behavior. Sometimes a chaplain working with AIDS patients needs to be confrontive, especially if a soldier is exhibiting denial.

Another area of practical ministry where the chaplain needs to be involved is in the interaction with the medical staff. Doctors and nurses, trained to fight to save life, may have difficulty caring for patients with no hope of recovery. Most of the victims of AIDS are young (late 20s to mid 40s). Young male doctors may identify too closely with those whom they perceive to be their peer group, whom they will be unable to save. The babies born with AIDS, the children who develop the disease from use of contaminated blood products, may also generate strong feelings within the medical staff. Dr. Arye

Rubenstein, of the Albert Einstein College of Medicine in the Bronx says, "Staff members regularly weep in my office. There is so little hope at the end of the tunnel." [8]

The chaplain serving a MEDDAC or hospital is in a position to minister to medical staff, AIDS patients, and family members. The hospital chaplain is the logical one to conduct classes in pastoral care for AIDS patients for other chaplains on post. He or she can be instrumental in getting the medical personnel to provide medical education for chaplains about the disease. Ideally every CONUS post and every overseas military community should have one chaplain especially knowledgable about ministry with AIDS patients who could act as a resource for others.

In our concern for the AIDS patient, we must not overlook the need for pastoral care for the primary care giver. Often, the primary care giver will be a family member. A person in this position needs support, prayer, and compassion; for no matter how lovingly care is given, the AIDS patient will eventually die. There is not the "reward" for the care giver of seeing the person get well. Practical support from friends in the area; helping with chores, shopping, preparing meals, and even sitting with the patient to give the care giver a few hours of relief can be a big emotional boost.

## What Is Different About This Disease?

AIDS is the most feared and dreaded disease in our society today. It is more feared than cancer, heart disease, or even auto accidents, which all kill far more people per year than AIDS. Mounting concern about the disease is visible daily; required testing of the civilian population is being debated. People who are AIDS-positive have been fired from jobs, evicted from apartments, and one man was even refused a seat on a airplane. Why this stigma? What causes us to recoil in horror, just as the people in biblical times shunned the lepers? There are several reasons which cause this reaction in people.

First, there is still much confusion over what is known about the disease. Although scientists repeatedly stress that it cannot be transmitted through casual contact, the attitude of many people seems to be, "Well, that's true for now, but what if in the future we find it can be transmitted by shaking hands or sitting on a toilet seat?"

Second, the disease, although it is spreading among heterosexuals, still affects a disproportionate majority of those who are not in the mainstream of society; *i.e.*, homosexuals, Blacks, Hispanics, Haitians, and drug abusers. "Normal" people do not want to be identified with these "wretched of the earth."

[8] "AIDS Children Struggle with Tragic Legacy," the New York Times, 1 July 1985.

Third, the disease forces us to think about the routes of transmittal. The sex act and blood transfusions are normally thought of as life-giving transactions between human beings. We make love to procreate or for pleasure. We give blood and sometimes receive it, in order to save life. Intravenous drugs can save life if they are not abused. With AIDS these same acts bring on death. It's easier to pretend that AIDS can happen only to others, whoever they may be, never to me!

All who claim the name of Christ are called to minister to one another in good times and in bad. Chaplains in the military find themselves in a unique position to minister to all sorts of people. The AIDS epidemic is a reality; it is here to stay, and there are no easy answers. Our faith calls us to stand with those who are suffering, to offer the promise of forgiveness, and the hope of the Resurrection.

Ministry with AIDS patients is not easy. It calls for a thick skin, patience, endurance and tears. It calls for the ability to speak to a commander and say, "Sir, this person is a human being, no matter what kind of disease he has." We must confront our personal fears on the subject, and find the courage to stand with those who face a painful and lingering death.

In *I Corinthians* 13, Paul writes "These three things remain, faith, hope and love, and the greatest of these is love." Our greatest gift in ministry is our ability to communicate to others in need that God's promise is firm, and that God's love does not desert people in the face of pain, death and AIDS.

## Breaking New Ground

# The UMT's First Training Response To AIDS In The Army

**Ralph Benson**

AIDS was a major headline in the fall of 1985 and the hysteria that surrounded this killer virus that seemed to strike homosexuals grabbed the news media by storm. Chaplain (MG) Patrick Hessian, after reading an article on this disease, anticipated a need for pastoral care for those with the disease in the Army. How would the armed services react to this situation? He called the commandant of the Chaplain Center and School and gave him a "heads up." "Be ready to respond to the needs of soldiers and their families with AIDS," said the Chief.

At that time, I was a new instructor at the school with a degree in statistics and evaluation. My only interest in AIDS had to do with the possible use of the medical data as a contemporary and unique area to complete my degree program. As I entered the commandant's office for my initial briefing, I had no idea that the Chief of Chaplains had just called with a request to get ready for a possible research and training mission. As the conversation continued, I mentioned that I was completing my degree work and was thinking of using AIDS as the subject area. I could see inspiration in the commandant's eyes when he asked me to think about research in the area. The next day I was asked by my division chief to begin collecting research data on the subject.

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Chaplain (Major) Ralph G. Benson has served as an instructor and writer and as the Director of Evaluation and Standardization at the US Army Chaplain Center and School, Fort Monmouth, New Jersey, since September 1985. He wrote the first training support packet on AIDS in February 1985 and has spoken extensively on the subject throughout the chaplaincy.

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Four years ago there was very little information coming from the pastoral care community concerning AIDS. The popular press fanned the flames of hysteria while the medical community struggled to develop a clear medical model of the disease. Searching the data base on pastoral care, I found one article that addressed the problem.

The medical statistics were grim. The disease was a killer. However, I was convinced then that transmission was connected with the sexual behavior of homosexuals and therefore limited to the gay community. This personal opinion may in part explain the religious community's slow response in meeting the pastoral care needs of dying people. For me and perhaps for many chaplains, the stigma of homosexuality had to be dealt with first. AIDS was "an ethical issue" and "sinful behavior" overwhelmed the church's thinking. The church, like the news media, reacted to a moral issue rather than responding to the spiritual needs of dying people.

My own personal thesis area was shattered by Dr. Redfield of Walter Reed Army Medical Center. He was certain that AIDS was a venereal disease transmitted by blood and that the exposure was not limited to homosexual behavior. He felt exposure to the disease was much greater than projected and that heterosexual transfer was a fact established by data already collected by the Army. He thought AIDS would be an international issue within a few years. I had no idea how prophetic those words were to be.

Based on the recommendation of Dr. Redfield, I interviewed six soldiers and twenty-three civilians who had been exposed to the virus. The faces of these individuals and their feelings of helplessness are still a vivid memory for me. Each shared a similar story. They were sexually active and had no idea they had the disease until they continued to get sick. They were filled with despair. They were shunned by hospital personnel, could not easily tell their parents or spouses, and had no idea what the future held for them.

These young people were not homosexual, and what if they were. They looked like the many soldiers that I had known when I was a battalion chaplain. They were married. One had been involved with drugs and quit. They were dying; and what was my responsibility as a pastor? As I left those interviews, I began to struggle with three areas of thought and concern that were to be essential to my personal growth and for my ability to develop training in the area of pastoral care.

First, I had to deal with my fear of contagion. I began to wonder, could I have been exposed by talking with the people? What about my wife and family? This fear seemed to come and go, but it was always in the back of my mind. What if I were exposed? I had read all the information available and was convinced, at least cognitively, that the virus was not spread by casual transmission. I had even written a short draft training support packet on the facts of

transmission. I was still plagued with the fear. I even took several blood tests to ensure that I had not been exposed.

I have yet to completely work through this passage; however, I gained strength through talking with other professionals working in the area. Just to understand that they had the same fears was helpful. I was not alone in my struggle. This communication also helped reinforce what I knew congnitively. This was an irrational fear. Once I decided to change my thinking about contagion, I gained the strength to continue my work.

Next, I had to deal with my fear of homosexuality. It was a fact that many of the people I dealt with were not homosexual. However, the majority of successful support groups were and are staffed with gay personnel. My stereotypes, conservative background, and negative early childhood experiences with a homosexual uncle, played a role in generating a masked fear. I tried to be very open and understanding of homosexuality, but I was putting up a front.

Over a cup of coffee and a bagel, a gay staff member of a New York support group confronted me. "There seems to be a wall between us . . . what's going on?" I tried to make excuses, but he didn't buy them. I began that afternoon to work through my fears. I had to realize it was okay to be "straight." Most people in the gay community are not trying to make converts. They are dealing with a crisis. Homosexuality didn't "wipe off" through these relationships, and my understanding of homosexuality has been greatly expanded by dealing with the gay community. I had to face my fears and come to understand that homosexual behavior is not caught through relationships.

Finally I had to deal with my own struggle with death. This may have been the most difficult passage for me. The people I dealt with were all younger than me. I began to deal with my own finitude. What was causing my passive resistance? Why was it so hard to write this training material? What was blocking my creativity? Finally it came to me. I was afraid of death. Like the other areas of contagion and homosexuality, I had a cognitive understanding of what was going on, but I had not dealt with the affective domain.

Talking and reading about death scared me. I had to begin to realize that it was okay to be angry about this hopeless situation with no answers. How could I write training with no answers?

I began to research support groups hoping to find some insight into my own struggles. I found direction for my discomfort with contagion and homosexuality by talking with other people. Instinct forced me to reach out to others. Through my many contacts in the New York area, I found several successful support groups. I joined the one I felt comfortable in, and then one evening I confronted the group with my struggles. I was afraid of death.

I was working and researching an area that scared the hell out

of me. I was plagued with my fear of being exposed to AIDS and yet frustrated by a hopeless situation. That outpouring was needed. The group helped me get in touch with my own feelings and helped me accept the fact that it was all right to have feelings. Insight and direction come by realizing that cognitive knowledge has to be tied to emotional understanding. It was one thing to know about something, however it's entirely different to combine knowledge with emotions. It was in a support group that I found the same areas that gave direction to these dying people gave me insight as a pastor. We talked openly about God's grace, forgiveness, salvation, and eternal life, that each person has just one day to live, and must live it to its fullest. The group members were dying and knew it. I was dying and hadn't accepted the fact yet. The only strength we had was each other and God's word.

The group experience forced me to re-evaluate my own spiritual journey and to find new hope and strength in Christ's words of assurance and forgiveness. Grace had new meaning for me after I was willing to get angry with God. I cried and shouted, struggled and prayed, and then peace came. I imagined Christ saying, "Don't worry, Ralph. I can handle your mortality and the mortality of all these young men and women dying with AIDS. Just be faithful, accountable, and teachable. My grace is sufficient."

I realized that each member of the support group found it was part of the human condition to be afraid, to be angry, to feel the depths of hopelessness, and that in the end, hope finally came if you were willing to struggle and to be completely open. I became a pastor care-giver, not in my strength but through exposing my wounds.

I began to realize that pastors have a lot to share with these dying people. The AIDS crisis reaffirms the church's role of reconciliation and healing. The hope that gave me strength and direction gave those exposed to HIV strength and direction as well. A poastoral care response demands working through our fears of the disease and our finitude and then sharing honestly the hope we have found in a personal faith in Christ.

It was after I worked through my own struggles that I found the creative energy to write the Army's first training support packet on AIDS. It came together in less than a week. The thesis came from my own personal struggle to understand what was going on in the world around me.

As I have continued my research in this area, it is evident that the Army chaplaincy needs to re-evaluate its role in dealing with exposed soldiers and their families. Training programs are too cognitive and driven by charismatic personalities. A holistic approach is needed.

Leaders on a unit level need to share their feelings and fears in connection with AIDS and HIV-exposed soldiers openly in group

sessions with trained professionals. Leaders need to know they are not alone in their struggles, and that exposed soldiers and their families present the Army with a unique training opportunity. What are we going to do with soldiers who are NBC casualties? We know very little about treatment for these soldiers. There is the same fear of contamination. They will not be a combat asset. But they will be people with dignity and worth. What is the ethical response to their case? HIV-exposed soldiers present us with an opportunity to deal with our deepest fears. And these fears can be resolved through a spiritual re-evaluation.

I pray that leaders can respond from their heads and hearts rather than reacting. I personally believe that a comprehensive program of support can and has been developed on some installations for HIV-exposed soldiers and their families. The Army has an opportunity to be on an ethical growing edge, and the UMT has a spiritual responsibility to risk being a wounded healer in order to present the gospel message of hope in a situation and circumstance that appears hopeless.

# Issues In HIV/AIDS Ministry

**Robert W. Schellhaas**

"Welcome to Walter Reed," said my new boss, Chaplain Frank Beltran. "You'll be working with orthopedic, neurosurgery and HIV/AIDS patients." My countenance didn't reflect the question marks that filled my head. My CPE training a year before had taught me to deal with this sort of news without feeling threatened. Or, so I thought.

Sure, we had "AIDS" patients at Brooke Army Medical Center when I was there for CPE (Clinical Pastoral Education). I think I "actually saw one." But I never really talked or ministered to one of the people who were affected by this new subject of worldwide attention.

And now, because many soldiers who tested HIV-positive (HIV+) on two tests were being sent to Walter Reed Army Medical Center for staging, evaluation, and return to duty or possible medical board, I was to minister to AIDS patients. (The process for determining the degree or level of effect the HIV virus has made in an individual is called staging.)

At the start of the ministry I was covering between fifteen and twenty HIV patients, depending on the week-to-week bed census. But within six months this increased to an almost constant patient load of close to forty, plus ongoing interaction with outpatients. Frank covered another section of the ward for several months more, as well as helping to lead a twice-weekly mandatory HIV Support Group on the ward.

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Chaplain (Captain) Robert W. Schellhaas has been the ward chaplain for HIV/AIDS patients at Walter Reed Army Medical Center since January 1987. He received his B.A. from Thiel College with majors in history and religion. He received his M. Div. from Gordon-Conwell Theological Seminary and his Ph.D. from California Graduate School of Theology in Psychology of Religion. He completed four quarters of Clinical Pastoral Education at Brooke Army Medical Center, Ft. Sam Houston, Texas. His assignments have included serving with the 24th and 25th Infantry Divisions.

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"Wait a minute! Do I have to wash my hands every five minutes? Do I have to wear a gown or an NBC suit or something?" These were questions that were going through my head, and I was trying to find how to tactfully ask Frank these questions. I barely had time to deal with my very mixed feelings before I was suddenly on the ward, meeting staff and patients and getting the grand tour.

I soon found out that my patients, for the most part, were in reasonably good health. The ward was officially known as the "Self-Care ward," for patients who were well enough to eat at the dining facility on another floor and to get around by themselves. The floor's population also included several non-HIV patients. These non-HIV patients were primarily in for radiation treatment.

I began to reason that these same HIV patients were flesh and blood human beings. They roamed the same halls, and they ate in the same dining hall with soldiers, staff, and other patients. Still, it seemed different to be interacting with them, one-on-one. I had to give myself permission to feel a little insecure inside, and knew, or hoped that these fearful feelings would eventually fade with experience.

As I became involved with the HIV patients, I found that the issues and problems at hand confronted me very quickly. New issues of patient care and human need challenged me and helped me to overcome and forget the initial reactions I had felt.

A young mother was on the ward. Her three-year old son roamed the halls in search of adventures and friendship. The father-husband was a patient on the same ward in another room. The mother and son were both HIV-positive. The father was HIV-negative but had some similar symptoms.

The woman, in her early twenties, was from Haiti. I remembered that Haiti had a higher percentage of HIV persons. Without letting it affect my interaction with her, I was already forming opinions about her morality and that of her husband.

But the next day, in our weekly multi-disciplinary staff meeting, we reviewed each patient's status. A doctor said that she had apparently had a difficult labor in delivering her son and had received a blood transfusion at an Army hospital. This was the source of her HIV.

She was also currently three months pregnant, I heard. Furthermore, she called herself a Christian, and her mother was an avid Pentecostal who was currently staying in the area, praying for a miraculous healing.

One doctor was strongly recommending for her to have an abortion. He said that carrying the baby through delivery would increase her HIV staging. The chances were 75% that the child in the womb was already infected, he said. Who would care for the children

when the parents died? And why go through the heartache of having a child suffer from HIV?

Another doctor took exception to this and said the mother would probably not get any worse from the pregnancy and that the chances of the child becoming infected were much less. Besides, he said, many children are born with problems but that doesn't make them any less a blessing to the parents.

Abortion is a hot issue in itself, but add the HIV dimension and one's ideas, opinions, and feelings are freshly challenged. I found my conservative beliefs exercised with new data in light of this new ethical situation; and although my stance did not change, my brain burned up a lot of calories in soul searching.

Another woman, an HIV patient and mother of a pre-teen daughter, contracted the disease from her husband who was sent to prison for a crime. She remained faithful throughout his sentence and for a welcome-home present, he brought her the HIV virus. While she was hospitalized, he was wanted by the police and civil authorities in another state. She did not know his whereabouts. Was she sinning because she had a boyfriend who loved her despite her HIV infection? Anyone who presumes to have standard answers or rigid beliefs can expect to be challenged when dealing with the issues related to HIV and AIDS.

Despite being diagnosed as HIV-positive, some patients continue their promiscuous lifestyles. One patient reportedly said he did not care what he gave to someone else.* As a result of his unconcern, the command ordered all military personnel who were HIV-positive to practice "safer sex." (There is no "safe sex.") This action was taken both to protect unassuming sexual partners and to deal with the liability which might fall back upon the military structure.

Several weeks after this action, a female soldier patient reported that her boyfriend refused to practice "safer sex" or to wear a condom. He was not HIV-positive, and he said that condoms disrupted his pleasure. We were faced with a new and difficult question: how does one enforce a rule upon a female soldier that orders her to use a condom? There were no easy answers.

What were the rights of the married couples who were patients on the ward? Were they to be allowed to share a room and to attempt to restore the environment of home while in the hospital?

A number of the HIV patients were openly proclaiming their gay or bisexual lifestyle. They lived on the same ward and shared rooms with four or eight persons. Were they to be permitted to openly show affection in the hallways? What standards were to be

* This behavior can sometimes be associated with neurological damage from the HIV virus. Various terms are used for this such as AIDS dementia, CNS (Central Nervous System) involvement and other terms which are more specific to the areas affected. See article: "Neurological Complications of HIV" by Susan Fair.

enforced upon their behavior? What right did the hospital have to suggest the superior moral value of a married heterosexual couple by giving them a private room while disallowing homosexual expressions of affection?

In these discussions, deliberations, and decisions, the major guiding factor was that the hospital is an Army facility and the official military view which disallows homosexual behavior was enforced. Besides, many of the soldiers were still on active duty and were liable to UCMJ action with regard to sexual and moral behavior. Married couples were accommodated with private rooms as space allowed.

## New Disease and Old Issues

It would have been easy for me, even as a chaplain, to retreat into a morass of ethical and moral issues and to play Junior JAG. However, I have been called first to minister God's grace and compassion to the suffering and afflicted. This asks for the ability to "love the sinner" and to minister without rejecting the person. Yet, I am also called to hold firmly to the beliefs which have been hammered out through experience and the study of Holy Scriptures. Both dimensions of ministry were required of me.

Some patients who came from a conservative Christian background expected the chaplain to uphold traditional values and openly to acknowledge and label sinful lifestyles. Their need was not to be told they were "okay" but to be told that they were loved and accepted despite their sin, for which they found forgiveness through confession and not through denial.

In examining the ethical issues, I gradually discovered that sin and sickness come in many forms. If a pastor has a well-thought-out ethical approach, however, he or she will be able to work from this position to match the same old issues to their new settings. One's pastoral "basic training" should have provided the tools necessary to approach the "new issues" of HIV.

Certainly, one must be open to re-examine ethical and moral positions and to approach new issues fairly. But as I did so, I found that the old answers for the most part fit the new settings. And through the challenging process I was able to find personal growth and an appreciation for the soul searching that my patients were going through with their own issues. I was able to walk with them, hurt with them, and yet to represent my faith to them.

## Pastoral Care: Attitude

Recently a group of chaplains came to Walter Reed for two weeks of study in a course introducing hospital ministry and training. When I spoke to them about my work and experiences with HIV patients, I

had them put a finger in each ear, and I said, "The biggest problem I have encountered with HIV ministry has been between the two fingers." One's personal feelings, fears, and views are the key issues which each chaplain must deal with in order to minister effectively to HIV and AIDS sufferers.

Although I found myself returning to my original moral and ethical positions, I found also that my most challenged area was not in my beliefs but in my judgment. It was the ability to love the sinner and hate the sin that challenged me the most. Even the slightest appearance of non-acceptance toward the HIV sufferer sets up a wall and barrier to ministry that cannot be crossed.

Because of the moral judgments so frequently connected with the virus, the HIV sufferer is probably the most insecure patient one encounters. This social branding and stigma is nothing new. When I was a teenager, anyone who came down with mononucleosis was immediately teased about their "kissing disease." There was a moral stigma about the illness.

In the biblical story of Jesus and the blind man, the religious authorities of the day said his illness must have been caused by some sin. If the man was born blind, then his parents must have had syphilis, a disease of the sinful, it was thought. In the same manner, HIV sufferers are frequently branded with a red "A" (for AIDS) by others. Even the confusion which labels all HIV-infected persons as "AIDS patients" shows the level of ignorance that most of us have. (See "Understanding Human Immunodeficiency Virus Infection" by Jeffrey Lennox, M.D., in this issue.)

A self-inflicted wound? Some people feel that the HIV infection is a self-inflicted wound in most circumstances because of the nature of its transmission. However, many diseases that we work with in our day could be construed as self-inflicted due to the irresponsible behavior practiced by most of us fallen human beings. If someone smokes for years and suffers from cancer, for example, we might feel sorry for their having smoked and sense a kind of tragedy, but we might also say, linking the behavior with illness, they asked for the disease.

Being overweight causes a number of stresses on the human body which can result in diseases. Having frequent displays of anger can do other damage. Lack of exercise or proper self-care is another means of self-inflicted injury through passive neglect. At what point can we draw the line between sin and sin? All fallenness involves suffering and since most religions incorporate some view of the fallenness and tragedy of human existence, how can we distinguish between the value of one human life over another by such an arbitrary measure as the ailment which attacks them?

Even if one can persist with negative feelings about one type of human being or another based upon behavior, how can one deny

grace to individuals who have sought and found forgiveness or who are seeking it according to their religious faith?

The "implied guilt" which we can so easily find ourselves assuming toward HIV-positive sufferers can seriously undermine our credibility with those to whom we are called to minister. This can be especially devastating with the occasional "false-positive" HIV person who later proves to be HIV-negative. One soldier was shipped prematurely from Germany, and because of the way he was dealt with by command and others, after several months waiting to prove him non-HIV infected, he was medically retired based on psychological trauma.

On one occasion I agonized with a woman and her infant who waited for a week on the ward before finally being told they were both HIV-negative. Had she been treated with the stigma which some persons attach to HIV-positive persons, the effect could have been devastating. Instead she was able to return to a normal life with only the shock of a close call.

Issues related to "false-positive" become increasingly common as mandatory testing or mass-testing techniques are introduced. Kodak recently announced plans to market a kit known as "SureCell" which can produce highly accurate HIV results in a doctor's office within 15 minutes. With judgment so swift in regard to one's HIV status, the devastation of the occasional false-positive individual is heightened or diminished by society's moral judgments and attitudes toward HIV-positive persons.

Clergy are challenged at this point to apply the grace which they preach and to withhold throwing the stones of judgment. The responsibility to preach compassion, not judgment, falls upon us as we seek to educate persons, parishes and society with the truth.

Although sin may be involved in the acquisition of this dreadful disease, I have no right to judge; I am only called to minister and to care. If I am to be a prophetic voice in challenging an individual about sin, I must first be an agent of God's love and a bearer of Good News. With the HIV sufferer, this can only come through my acceptance.

This acceptance becomes obvious to the patient in a number of simple ways. When the HIV patient offers a handshake to the chaplain, rubber gloves are not required. A human hand, offered by the pastoral care giver in response, may be the key to further ministry with this person.

Eye contact, essential in all pastoral care, is especially important with these patients. The eyes are the window of the soul and the light of the body. The patient can sense the chaplain's openness or lack of it through eye contact. The chaplain has the opportunity to send a message of care and sincere compassion

through this interaction, even if the patient's own lack of self acceptance or shyness causes him or her to avoid eye contact.

I have been asked frequently if HIV/AIDS can be caught through this casual contact. We are assured by the experts in the medical field that it cannot be transferred in this manner. I trust in their position. And if they are wrong? Well, then I must practice my own faith and trust my God who has placed me to minister here with the "lepers" of the nineteen eighties. If my own safety and the safety of my family were foremost on my mind, I would be unable to be of any use in God's service. I take the accepted findings of science and deal with my feelings as they come.

The experience of the experts and of all who have worked with HIV-positive persons shows that the probability of getting the virus through casual contact is zero, or almost absolutely zero. Still, we maintain healthy life habits by hand washing, and taking care to avoid the exchange of body fluids.

## Pastoral Care: HIV in Perspective

There were 300,000 cases of hepatitis B in the United States as of January 1988. There were 20,000 health care workers infected with this deadly disease, and there have been 200 fatalities among health care workers. This virus which can cause liver cancer and death, is more persistent than the fragile HIV virus. In comparison, there are 53,000 persons with AIDS and 1-2 million persons with the HIV virus (possibly many more with the virus who are unidentified), and only 14 health care workers who have become infected, with zero fatalities. All HIV infections among health care workers can be specifically traced to events far beyond casual contact with HIV patients.[1]

The leading cause of death in the U.S. is coronary artery disease, with over 600,000 deaths each year. And about 800,000 people in the U.S. are diagnosed with cancer each year. In young adults, traffic fatalities account for many more deaths than any disease.[2] Despite the fact that the HIV virus is one of the most devastating infectious diseases known to the world, the pastoral care giver must in a sense demythologize the virus and the HIV positive patients in order to provide a realistic perspective for their approach to another human being in need.

Fascination with a seemingly new crisis for humanity gives HIV and AIDS much of its power and mystery. It also causes most of our self-imposed stumbling blocks to effective pastoral care. "What has been will be again, what has been done will be done

[1] Interview with Head Nurse, HIV Ward, Walter Reed AMC, March 1988.

[2] "AIDS: Putting the Problem in Perspective," Medical Abstracts, January 1988 (Volume 8, Number 1).

again: there is nothing new under the sun. Is there anything of which one can say, "Look!" This is something new? It was here already, long ago; it was here before our time." (*Ecclesiastes* 1:9-10)

As far as our professional ability to minister to HIV/AIDS patients, each chaplain has at least some experience or training in basic areas which are relevant to this ministry. The virus is seemingly new, but we can draw upon our own existing internal resources and adapt them to this new avenue of ministry. The areas of approach for working with HIV/AIDS patients fall into basic categories which should be familiar to all pastoral care givers. They are grief ministry and goal-setting. These areas of ministry and pastoral care effectively address the problems of boredom and purpose.

## Grief Ministry

Grief ministry is appropriate at the time of notification when the person is told that he or she or a friend or family member is HIV positive, and in various stages of the disease's progression as well. Most of us are aware of the standard five stages of grief: denial, anger outward, guilt (anger self-directed), genuine grieving for loss/pain/loneliness, and finally the resolution and reincorporation of life's elements.[3]

In my work on the ward I find that each person is an individual with different responses to the grief process. Some have already had time to prepare and to reason about the probability of loss before it takes place. If their lives are in good order before the impact of notification, recovery seems easier. Others are caught without preparation and react adversely to the grief process.

I find that some patients who come to the ward who have been diagnosed less than a week are handling their grief well, having decided long ago that their lifestyle has left them vulnerable to the HIV infection. Others that are on the ward for the first time are still in a state of disbelief and shock.

The same holds true for some who have been HIV positive for months or even a year. They may use denial logic that says God will cure them, that they have nothing to worry about because science will find a cure before they have to worry about losing their lives. Some never move beyond the basic stage of denial. Many reflect a generally irresponsible view toward life and never seem to have learned to deal with conflicts or responsibility.

Some have gone through the grief process in a former visit to the ward and are returning for a follow-up exam. They are readjusting to a potentially disabling virus by watching their health

[3] Wendler, Klaus, "Ministry to Patients with Acquired Immunodeficiency Syndrome: A Spiritual Challenge," Journal of Pastoral Care, March 1987, Vol. XLI, No. 1.

and diet, getting rest and exercise, obtaining a job or becoming gainfully employed with their time and energies. They have the attitude that the virus is present, but not currently affecting them. In many cases this is true for the "healthy" HIV-positive person.

Some persons say that their lives are more worthwhile since they have found they are HIV-positive. They say it has challenged them to re-evaluate priorities, values, and spiritual beliefs. (See "My Existence with the HIV Virus" by an staff sergeant in this issue).

The pastoral care giver at the point of notification has one major role: the ministry of presence and acceptance. By being there and reflecting the person's views in an accepting and caring way, the chaplain establishes herself or himself for a long-term impact. Helping the person to deal only with the issues that the person is prepared to work with sometimes leaves the chaplain with a feeling of helplessness or anxiety over what to do when growth is stalled. The person will only grow when prepared to do so.

## Goal Setting

Setting goals is difficult if one perceives the options to be severely limited. However, providing a new vision within somewhat confined limits is possible, and is necessary to empower the individual toward positive living. Once a person feels some future-oriented possibility and feels empowered to control it, the person can begin to set goals with specific objectives for reaching these goals.

Basic courses on leadership and management, values clarification, and human empowerment can further enable a pastoral care giver to facilitate this process. If a patient is open to religious ministry, the vision of a powerful Holy Spirit is invaluable in this regard.

I teach a weekly, mandatory "Life Values" class for all patients who arrive on the ward. Because the class is mandatory, I use a secular approach, but I am still able to "own" and articulate my personal faith perspective. I am sometimes surprised by the number of HIV-positive patients who have strong fundamental, conservative Christian beliefs. Most patients voice some faith in God although they may not be able to fully define their beliefs.

My class begins with a very common metaphor. I call it the "Toilet Bowl" theory for doing things. When we go to the field and are progressing quickly, we are not very concerned about where we "do our business." But if we are in one location for a length of time, sanitation becomes a concern, with latrines dug out and maybe even an overhead tent. In society we use clean porcelain, long-distance plumbing, and we try to move our sewage as far from us as possible.

In life we use the same strategy. If we are unempowered and lack vision, we let unpleasant things pile up around us irresponsibly.

The greater our vision of purpose and sense of empowerment, the harder we try to resolve conflicts and to keep our sense of reality healthy.

This brings about the other issues which I teach in my class—our personal values and our ethical interactions. True values are the things which motivate our behavior. False values are the things we pretend we believe, pay lip service to, and find ourselves obeying half-heartedly. Finding one's true values through examination of childhood and upbringing, religious beliefs, and cultural training can liberate an individual to live an empowered life.

Choosing our values, however, does not give us permission to abuse someone else's values. Ethics becomes an important issue of accountability and responsibility to others. "My rights stop where your nose starts" is a common phrase. I can swing my fist all I want, but I do not have the right to hit you in the nose because it violates your value of peace and your individual rights.

After presenting these ideas in a condensed format, I usually find issues related to ethics, values, or morality that get the patients involved in discussion or arguments. The scenario of who in the room gets the only life-saving injection stimulates emotions and interaction. Inviting patients to share incidents when they are discriminated against or were rejected due to their HIV-positive infection also can lead to lively and important discussion.

After the patients are engaged, I present the challenge to evaluate what goals and objectives they are setting. We discuss how most organizations have a one year plan or a five year plan. I invite them to consider what is most valuable to them and what they want to achieve. I also include realistic views of the conflicts they might encounter, and the need to learn to resolve conflicts rather than to give up. I encourage them to utilize chaplains, counselors, and friends to help them work through the finer details of their issues and plans.

By dealing with practical issues the patients are put in touch with their still-viable life. They find themselves empowered by their emotions to deal with the issues at hand, and they are then able to find a cause that invigorates them toward goal setting.

## Boredom Ministry

Boredom ministry should be familiar to anyone who has deployed with units that "hurry up and wait;" groups which are deployed quickly and then allowed to spend days or weeks waiting to be put into action. Providing structure and continuity are key elements for fighting boredom.

In the field I found a nightly chapel service after the evening meal met this need for ongoing pastoral care. When I first started on the ward, the HIV-positive patients were treated like other patients—they were left in bed and in pajamas. Most of them, however, were

not suffering any acute illness and the lack of structure and purpose only contributed to depression. Now they are out of bed at reasonable hours, wear street clothes, go to the cafeteria to eat, and they are known as Self-Care patients.

Several months ago a Ward Community Council began. A weekly meeting is held and attendance is mandatory for the patients. Officers are elected and replaced as patients leave. The patients are contributing members of a social group which brings empowerment to the individual. As a result of the Community Council, several problems have been confronted successfully. Difficulties with hospital maintenance and housekeeping have been resolved. The structure has also provided a means of meeting the patients' human needs as they move together to express concern and support for one another. This last Easter, for example, the patients voted to have a party for the pediatrics ward. They planned an egg hunt, coordinated the food and supplies, and were rewarded with the secondary gain of satisfaction from their organized expression of love.

## Multi-disciplinary Staff Approach

There are a number of professional areas represented on the ward at Walter Reed Army Medical Center. There is a psychiatrist dedicated to the ward. A neuropsychologist does psychological screening and evaluation in order to find organic effects of the virus. An art therapist works regularly with the patients in order to help them express their feelings indirectly through artwork and to provide a therapeutic outlet. Social workers regularly counsel patients and hold mandatory group meetings twice weekly. A social work technician is present to work out practical issues. A ward physician is resident on the ward. A nutritionist gives classes and helps patients to adopt healthy eating habits. The ward chaplain coordinates issues with each of these individuals as a vital member of the HIV Staff Team.

At any installation or in any community these interdisciplinary staffs are available to the pastoral care giver. Each member of the clergy needs to know contact points in the likely event that he or she will have an involvement with HIV positive persons or their families.

## Conclusions

Each pastoral care giver must have a solid knowledge of the myriad issues related to HIV illness and its implications. Thinking through these issues in relation to one's faith is imperative as preparation for the inevitable involvement which awaits each of us.

Having an operational plan is not only good military management but sound practice in preparing to minister to persons who are or who will be traumatically affected by the HIV virus.

Interaction with others who have worked with HIV-positive individuals provides a good basis of confidence and reassurance as well as a support-network for clergy who have not yet become personally involved.

Finally, due to the ever-growing wealth of information on the HIV virus and its effects, one must keep up to date with readings and findings.

# Understanding Human Immunodeficiency Virus Infection

**Jeffrey L. Lennox**

The illness which we now know as the Acquired Immunodeficiency Syndrome (AIDS) was initially described in 1981 by two groups of physicians in California and New York who noted the occurrence of an unusual form of pneumonia (*Pneumocystis carinii*) in young adult males. (1,2) This type of pneumonia had previously been common only in patients treated with cancer chemotherapy or immunosuppressive drugs. Following these initial observations, it became apparent that an epidemic of unusual infections was occurring in young males, intravenous drug users and hemophiliacs. The cause of this epidemic was unknown.

An important clue leading to the discovery of the etiologic agent was the fact that hemophiliacs were affected. The blood products that these patients received were routinely filtered to remove bacteria. Since viruses are much smaller than bacteria, the agent's passing through these filters suggested that it was a virus. The responsible virus was finally isolated by Montagnier, at the Pasteur Institute (3), and by Gallo, at the National Cancer Institute (4), in 1983. Initially these two groups each had a separate name for the virus. The virus was therefore called Lymphadenopathy Associated Virus/Human T-Cell Lymphotropic Virus-III (LAV/HTVL-III) until 1986, when its name was officially changed to Human Immunodeficiency Virus (HIV).

In the United States, it is estimated that there are one to two million people infected with this virus. (5) As of August 1987, 40,051 of these people had developed AIDS. (6) There are, therefore,

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approximately twenty-five to fifty HIV infected individuals for every AIDS case reported. By 1991, a total of 270,000 cases of AIDS are predicted to have occurred in the United States. (7) The majority of these patients will die within three years after being diagnosed as having AIDS. In some areas of Africa 5-18% of the population is infected with HIV. (8) Millions of deaths from this virus may therefore occur unless an effective treatment is found. Since this virus is presently most prevalent in young adults, its toll on society will be large. It is important that those caring for the victims of HIV infection, both the patients and their families, understand the scope of this illness. The purpose of this article is to briefly explain HIV infection and its associated illnesses.

## The Virus

HIV is a virus. Viruses are simple organisms composed of a few structural proteins and the associated viral genetic material. Viruses are dependent on the hosts they invade for most of the other materials necessary for their reproduction. The genetic material of viruses is either deoxyribonucleic acid (DNA) or ribonucleic acid (RNA). In almost all forms of life DNA is used as a template, or guide, for RNA production. RNA is then used as a guide for the synthesis of proteins. HIV is an RNA containing virus. Unlike other RNA viruses, however, it uses its RNA as a template to make DNA (the reverse of the usual DNA to RNA sequence), and hence it is called a retrovirus. All retroviruses contain an enzyme called reverse transcriptase which manufactures DNA using RNA as a guide. Once this has been accomplished, the newly formed viral DNA can then be combined or "integrated" into the host's DNA. The viral DNA becomes a part of the genetic material of the host. It can then remain latent for many years without causing disease.

Retroviruses have long been known to cause certain brain diseases and malignancies in animals. The first human retrovirus was isolated by Pojesz and Gallo in 1978 and was called Human T-cell Leukemia/Lymphoma Virus-I (HTLV-I). (9) This virus may remain latent for twenty years from the time of infection until the appearance of the leukemia which it causes. The latency period of HIV may be four years of longer. (10) HIV is related to a similar retrovirus called Simian T-cell Lymphotrophic Virus (STLV) which is found in Africa Green monkeys. The high prevalence of HIV infection in Africa and the occurrence of related viruses in African monkeys point to Africa as the original source of HIV. Positive blood tests for HIV infection have been reported on African blood which has been stored since 1959. (10)

## Transmission of HIV

The transmission of HIV requires that body fluid from an infected individual be transferred into a non-infected individual. Since the person with HIV infection may remain asymptomatic for many years, he or she may unknowingly infect many others. Exchange of body fluids may occur through sexual contact, needle sharing or blood product transfusion. In the United States testing for signs of HIV infection in all blood products for transfusion began in 1985. The risk of acquiring HIV infection from a transfusion after this date is estimated to be about one per million transfusions. (11) Unfortunately, perhaps as many as twelve thousand people became infected by way of blood transfusion prior to the availability of blood testing. Intravenous drug addiction can be viewed as a form of blood transfusion since addicts frequently share needles and syringes contaminated with blood. Intravenous drug addiction presently accounts for 16% of the cases of AIDS reported to the Centers for Disease Control (CDC).

Worldwide, the principle route of HIV transmission is through heterosexual intercourse. (12) In Africa the ratio of male to female AIDS patients is approximately 1:1. In the United States this ratio is approximately 13:1. This difference in the sex ratio of AIDS between Africa and the United States is because the majority of the men infected in the United States acquired the virus through homosexual intercourse. Since HIV infection usually remains latent for several years, these men were probably infected sometime around 1980-83. This long latency period means that HIV spread in a population may not become apparent for several years. If HIV infection is rare in a population, those who have sexual contacts with many different individuals will have the greatest chance of becoming infected. Once the infection becomes common in a population, fewer contacts are necessary for transmission to occur. Heterosexual transmission presently accounts for approximately 4% of US AIDS patients. Testing of applicants for military service detects latent HIV infection in almost as many women as men, with a male to female ratio of 1.2:1 in those areas of high HIV prevalence. (13) It is not known if these women had other risk factors for HIV infection. However, heterosexual transmission may be more common in the United States today than surveillance of AIDS cases would indicate. This is important since HIV infection can be transmitted from a woman to her unborn child. As heterosexual transmission becomes more common, so will cases of pediatric AIDS.

Those who do not share bodily fluids with an infected individual are at low risk of HIV transmission. HIV is not spread by toilets, handshaking, hugging, or sharing a room. Family members of HIV infected individuals have a low risk of acquiring the infection unless they are sexual partners of the patient. (14) Unfortunately,

many people remain ignorant of these facts. HIV can be transmitted if infectious blood comes into contact with a cut or abrasion. (15) In general, the only precaution necessary when caring for a patient with AIDS is to wear gloves when handling body fluids. In a hospital setting it may be difficult to know which patients are HIV infected. (16) This has led the Center for Disease Control to recommend body fluid precautions for all patients. (17)

## Diagnosing HIV Infection

Following infection with HIV, the body's immune system produces antibodies against the virus. These anti-HIV antibodies can then be detected in several ways. The most common test entails placing the blood to be tested into a small dish containing HIV bound to the dish. Any anti-HIV antibodies present will attach to the bound HIV. These antibodies can then be detected by adding enzyme linked anti-human antibodies. A chemical is then added which is changed by the enzyme to a different color. The degree of color change can then be measured. This test is called an Enzyme Linked Immunosorbant Assay, or ELISA.

The ELISA is rapid and sensitive, but it has many false positive results. It is best used to screen multiple patient samples to find any that might have anti-HIV antibodies. To confirm the presence of these antibodies, a second, more complex test called a Western Blot is done. Since this test is more time consuming than an ELISA, it is usually reserved to confirm the results of a positive ELISA test. Prior to the availability of these tests, HIV was only diagnosed clinically in its terminal stages (AIDS). With the availability of these two tests, we are now able to diagnose HIV infection in its asymptomatic stages.

## HIV Associated Illness

AIDS was the first recognized manifestation of HIV infection because it is the most severe sequela of infection. It is now obvious that HIV infection causes illness prior to the terminal manifestation of AIDS. The mechanisms by which HIV causes illness have not yet been fully determined.

What is clear, however, is that one of the hallmarks of HIV infection is destruction of the host's immune system. HIV accomplishes this by attaching to and invading white blood cells called T-helper cells. These cells are important in coordinating the body's immune defenses against infection. Once HIV infection occurs, the T-helper cells become progressively depleted. This depletion renders the immune system incompetent to resist infection. The patient therefore succumbs to repeated bouts of infection with organisms that would not usually be able to overcome an intact immune system.

AIDS was first recognized because of the occurrence of these "opportunistic" infections. HIV infected patients are also susceptible to malignancies such as Kaposi's sarcoma and certain lymphomas. The Center for Disease Control recently reviewed and reformulated the definition of AIDS. (18) A list of the infections and malignancies occurring in AIDS patients can be found in this reference. It must be remembered that AIDS is just one manifestation of HIV infection. Once a patient has progressed to fit the Center for Disease Control definition of AIDS, 85% expire in five years or less. (19)

Prior to this stage, many HIV infected patients have problems with weight loss, diarrhea, skin rashes and fatigue. These varied symptoms have been loosely described in the past as the "AIDS related complex" or ARC. One of the most severe early manifestations of HIV infection is its effect on the brain. At autopsy, 63% of patients with AIDS are found to have destruction of cells in important parts of their brains. (20) Recent studies have demonstrated signs of brain dysfunction in 54% (7/13) of patients with asymptomatic HIV infection. (21) Infants with HIV infection frequently show delayed motor development and failure to thrive.

It was the recognition of these varied manifestations of HIV induced illnesses that led Redfield and coworkers to propose the Walter Reed classification system in 1986. (22) This system attempts to classify all HIV infected patients, not just those who fulfill the Center for Disease Control criteria for AIDS. Patients are classified based on the results of blood tests for HIV antibodies, physical exam, T-helper cell counts, and the responsiveness of the immune system to foreign antigen injected into the skin. Based on these tests a patient can be assigned a stage from 1 (early infection) to 6 (AIDS). In a preliminary study of 62 patients classified in this manner who had been followed for 12-48 months. 57/62 had progressed to at least the next higher Walter Reed stage (DC Wright: Personal Communication). This classification system is useful for prognostication and possibly for studying results of drug therapy. Another widely accepted classification system has recently been proposed by the Center for Disease Control. (23) In this system, the T-helper cell count is not assessed. Patients are classified into one of four groups. All symptomatic patients fall into groups three or four. Further studies are needed before it is known which of these two classification systems is more clinically applicable.

## Treatment of HIV Infection

As detailed earlier in this discussion, retroviruses are unique in that they possess the enzyme reverse transcriptase. This enzyme is not found in normal, healthy human beings. A drug which inhibits this enzyme may therefore be an effective therapy for HIV infection. Several compounds have been found which inhibit reverse

transcriptase. The most useful compound to date has been azidothymidine (AZT). This drug is similar to a normal component of DNA. The HIV reverse transcriptase tries to make new DNA using AZT as a building block. Since it is an imperfect block, the enzyme is unable to complete its task. Manufacture of viral DNA, but not host DNA, is therefore inhibited. AZT was tested to evaluate its efficacy in 282 patients with AIDS who were treated with either AZT or placebo. Neither the patient nor his physician were aware of who was receiving the real drug. This study was halted when it became apparent that those receiving AZT had a much lower mortality rate than those receiving placebo. (24) AZT administration was also associated with significant weight gain and a temporary increase in the T-helper cell count. AZT is not a cure, however, since the virus could still be isolated from patients receiving AZT. Since completion of this study, AZT has been released for the treatment of any HIV infected patient. Because of its serious side effects, including anemia and depressed white blood cell counts, physicians at Walter Reed usually reserve its use for those patients with T-helper cell counts less than 200. Another drawback of AZT is the expense. The cost of one year of therapy with AZT is between seven to ten thousand dollars. Other drugs for treatment of HIV infection are presently being tested. It may be necessary to combine several drugs before optimal therapeutic efficacy is achieved.

## HIV and the Military

Members of The United States Armed forces are frequently exposed to vaccinations and exotic infections which can overwhelm a damaged immune system. In times of war, troops at the front frequently serve as "walking blood banks." For these reasons the Department of Defense established widespread testing of all active duty personnel and applicants for military service in 1985. (25) Those active duty personnel who have repeatedly positive blood tests are examined and assigned a temporary Walter Reed stage. Those with normal T-helper cell counts (Walter Reed stage 1 and 2) are counseled and returned to duty with a profile restricting them from receiving live virus vaccination and from serving in overseas assignments. They are then evaluated for progression of disease every six months thereafter. Those whom initial evaluation indicates immune system damage (Walter Reed stage 3-5) have a repeat evaluation in three months. If they continue to show signs of immune dysfunction, they are declared medically disabled. Walter Reed stage 6 (AIDS) patients do not require a repeat evaluation before declaration of disability. Walter Reed stage 3-6 patients are presented to a medical evaluation board (MEB) and physical evaluation board (PEB). It if is agreed that the service member is medically disabled, he or she is medically retired. Family members of HIV infected service members are also tested and

counseled. Applicants for military service who have a positive blood test are informed of the results and referred to a private physician.

This extensive system of testing enables military physicians to identify HIV infected individuals early so that the appropriate counseling may then be done. The service member benefits by being closely followed from the early stages of the disease. When treatment becomes necessary, the patient has already been thoroughly evaluated. The patient also benefits in that he or she can avoid unknowingly transmitting the infection to others. Until a vaccine is developed, limiting the spread of infection is the only method for slowing the epidemic. The Department of Defense has demonstrated that widespread screening and counseling can be accomplished. If HIV infection continues to spread through the general population, similar measures may soon be necessary in the civilian sector.

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## So Sarah Laughed

**Mama writes.**

> *The stranger said, "About this time next year, I will be sure to come back to you, and Sarah your wife shall have a son." Now Sarah was listening at the opening of the tent, and he was close beside it. Both Abraham and Sarah had grown very old, and Sarah was past the age of child-bearing. So Sarah laughed to herself and said, "I am past bearing children now that I am out of my time, and my husband is old." The Lord said to Abraham, "Why did Sarah laugh and say, 'Shall I bear a child when I am old.' Is anything impossible for the Lord?" (Genesis* 18:10-14)

I have always loved this story. Imagine Sarah's astonishment and bewilderment, thinking that such a joyful event was beyond realistic expectation, and, therefore, laughable. My spirits have always been lifted by the Lord's rejoinder, "Is anything impossible for the Lord?"

Now Papa, as we have come lately to call him, is probably not as old as Abraham was, nor I as old as Sarah, when the miracle of a baby came into their lives. But, we are well-established in middle-age, and turning the corner which will head us for those years understood by today's society as Senior Citizenship. What a euphemism—we're getting old.

We are not people of extraordinary talent nor vision, but average in most respects. Papa is a retired Army lieutenant colonel, and I, after twenty three years spent as what I hoped would be judged as "a good Army wife," am in the middle of my third or fourth mini-career. Papa pursues his second career in an academic environment. My present job has me working part time in an organization which provides assistance to persons with AIDS and to

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"So Sarah Laughed—Mama Writes and Papa Writes" is the personal reflection of the foster parents of a baby who has tested positive for the AIDS antibodies. Their identity is not revealed for the protection of the child and the family.

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those who love them and care for them. We live in the suburbs of a major city, and our lives are spent, in part, close to home, and partly in the city. It is there we first learned of hospice care, and where we began to volunteer time each week as patient care workers with the dying. In that setting we met our first AIDS patients, coped with our initial fears of the disease, and gradually overcame them. Along the way, we developed an increasing awareness of the isolation imposed by the community upon these patients and the suffering which stems from it. We saw their pain as, at least, as challenging to the community and to us as individuals as the symptoms and the issues of transmission, prevention, and cure. And so, I jumped at the opportunity to work with an organization in the church whose mission is to address those needs.

One morning, several months ago, I was working at my desk at the office. I hadn't slept well the night before because I had attended a lecture on AIDS, and the physician who spoke showed many slides, two of which touched me somewhere deep inside. The two slides were of children with AIDS, and of them he said, "There are hundreds of children like these in back wards of big city hospitals across the country. Although their nurses give them adequate care, they hold back somewhat because the pain of watching these children grow sicker and die is more than they can endure." Again and again during the night, I had awakened, remembering those pictures and those words. And then at my desk, a phone call came in from a staff member of a local Department of Social Services. She had questions about our organization: "What do you do? Do you offer support to health care workers as well as to patients and their families?" Then, just before hanging up, she asked if we might be able to assist in the recruitment of foster parents for infants born HIV-positive or for children with AIDS.* I answered, "Yes, of course, we'll try. I'm

*All babies are born with what is known as passive immunity. Each baby inherits his mother's antibodies to all the diseases with which she has been infected in her lifetime. These antibodies enter the baby's system through the umbilical cord. And so, for several months, the baby is protected against those infections by his mother's antibodies. After a few months, the mother's antibodies clear the baby's circulatory system, and soon, the baby's own immune system begins to operate. The baby produces its own antibodies to those infections which have entered its system. If a baby is born sero-positive (HIV+) for the AIDS antibodies, we know that his mother will test positive and that the virus itself is present in her system. What we don't know about the newborn baby is whether the virus was transmitted through the umbilical cord, or only the antibodies. The answer to that question is, "Wait and watch." The following possibilities lie ahead: 1. Perhaps he will test negative at about six months of age, and continue, after repeated tests over one to two years to test negative. Then the physicians will be able to state confidently that the antibodies were his mother's and that the virus is not in the baby's system. The child then has a normal prognosis and life expectancy. 2. Another possibility is that the baby will, at six months of age or so, test negative for the antibody, and then, some months later, begin to test positive again. This devastatingly disappointing turn of events is the result of a delay in the baby's immune system's producing its own antibodies to the virus, which was, in fact,

sorry I don't live in your jurisdiction because my husband and I would be glad to sign up." "Are you serious?" "Yes," I said. "We have talked about it." And so we had, about a year before, saying to one another, "How could anyone in our circumstances not be willing to take in one of these children?" We had even submitted our names to a local clinic which sometimes places such children. We had never heard from them and had not followed through.

The woman calling for the information took my home phone number; and that, I thought, was that. One hour later, the placement coordinator for that agency called and asked, "Are you really serious?" And then, "We have a ten day old girl who tests positive for the AIDS antibody. Her mother is an IV drug user who is unable to care for her at this time. Her other relatives are overextended in their commitments, and the baby remains in the hospital."

"I feel sure we will take her, but I need to ask my husband," I said, remembering we had not discussed the matter in a year. My brain was exploding, fragments of thoughts burst and vanished. So much to consider. I called Papa. He was out of his office. "Can we do it? Are we too old? Will we tire too easily? Are we patient enough? Are we competent to care for what may become a very sick child? Are we strong enough to be with her to death? Why can't I pray? I can't concentrate. How hard will it be to give her back to her family? Suppose she catches a cold or flu from us? Even if the Department of Social Services provides us with a day-care person, as they said they would, can I do a good job at work with the baby at home? Can I be a good foster mother when I have a job? What will our grown children and grandchildren think? Do we need their permission? Am I imposing this idea on Papa who is always so agreeable? Is this an ego trip? What about our freedom to travel, and to "live our own lives?" Why can't I pray? No crib, no baby clothes. What do they cost? How to rearrange the bedroom? The dog—will he behave? God wants us to do this—doesn't He? Formula, bottles. Can I go through that again? Why can't I reach Papa?" Think. I couldn't think. I couldn't pray. He directed my obviously wandering attention to *Romans* 8:26, "And in the same way the Spirit also helps our weakness; for we do not know to pray as we should, but the Spirit Himself intercedes for us with groanings too deep for words."

I was grateful to be reminded that the Spirit was praying for me. I xeroxed the page of the Bible because I wanted the passage handy. My concentration was at an all-time low. Then finally, I

in the baby's body all along. 3. Perhaps the baby will become symptomatic, as well as testing positive for the AIDS antibodies. 4. Perhaps the baby will continue to test positive, but remain asymptomatic. Current literature on AIDS suggests that about 50% of newborns who test positive for the HIV antibodies have the virus. Of that number, about 70% will develop AIDS and die within two years.

reached Papa. Just as I knew he would, he said without hesitation, "Let's go for it!" And we did.

We had not been foster parents before, and so the Department of Social Services had to do a criminal record and child abuse check on us both. There were autobiographical forms to file, references to check, and a hastily arranged interview at the DSS office by no less than ten workers from different areas of the foster care program. We met, too, with a social worker at the hospital, and a nurse there gave us a private lesson in infection control.

Almost daily, I spoke to the placement coordinator. Belatedly—because I had assumed that until all system were "go," issues of confidentiality precluded our learning the baby's name, I asked it. Kimberly. How wonderful a name is. It is an identification, to be sure, but, more importantly; it was a part of the developing bond between Kimberly and us. At last we could pray for her by name.

Clothes, disposable diapers and formula were purchased. One of our friends loaned us a crib; another friend loaned us a carriage. A friend of a friend loaned us an infant seat. Church friends brought their children's outgrown clothes and blankets.

At last the day arrived when we were to meet Kimberly. Gowned to protect her from germs which might lurk in our clothing, we tiptoed into her room. And there she lay in her metal crib, on her tummy with her head turned to her right. Such a tiny creature with wonderful, thick hair, long graceful fingers, a round bottom high in the air, bundled in a blanket, and attached to a monitor to record her heart and respiratory rates and to signal an alarm if either should stray from parameters set for her size and age. (Because of her mother's drug use, she was at increased risk for Sudden Infant Death Syndrome, and therefore was expected to be on the monitor for three or four months until the dangers of the drug's effects would be over.)

We held her and sang to her and visited her twice a day—always at feeding times—for that last week before we could take her home. We met her mother at a meeting arranged by the Department of Social Services caseworker and the social worker at the hospital. It was a tense and scary time in anticipation, but the meeting went very smoothly. To be sure, it is terribly awkward to face someone whose newborn child has been taken away from her and who recognizes you as those persons who have been deemed fit (fitter than she) by a government agency to care for her. We stressed to her that we knew that this would be a temporary situation, and that we would love Kimberly and care for her until she could be returned to her. The young mother was remarkably gracious, under the circumstances, saying that she felt better for having met us.

Two and a half weeks of preparation, shopping, and planning were almost over. Two hospice friends of extraordinary character

came forward and offered us their time and energy. Though they were both extremely busy in thier own lives, they volunteered to sign on as babysitters. The college freshman daughter of one of them enlisted, too. The three of them joined in taking special training in infant Cardiac Pulmonary Resuscitation; and on the day of Kimberly's discharge from the hospital, we attended the class on the operation of the monitor.

Throughout those two and a half weeks, we laughed a lot. Joy, of a magnitude we had never imagined, filled our hearts. What an opportunity to serve Him. He blessed us with this amazing joy. It overpowered our doubts and fears and streamed into a sense of divine encouragement and strengthening. He returned to us during those days of preparation old friends we hadn't seen in too long a time. He blessed us with the loving support of our own children. He built our defeneses for us, and increased in us both an awareness of His presence, His power, and His love.

**Papa writes.**

In many ways it was not unlike bringing home our first-born. The adventure was fresh and exciting, but there was an awkwardness. Kimberly was an exceptional person entering our lives (and we entering hers), and we were flushed with the moment and could only rely on God's continued faith in us to serve Him through our new charge.

Our grandsons beamed when they served as escorts on the trip home from the hospital. We knew right off how much we, Mama and I, needed to share Kimberly's stay with us if there were to be the loving environment we yearned for her to have.

We discovered early on, however, that there are those activities that don't require two people to complete, and especially a pair positioned in tandem. We arrived home with an apnea monitor that was not "portable" as described. Being exacting in our caution we ventured to travel within the house only by twos: Mama in the lead with Kimberly's carrier and in procession, Papa with the monitor's

carrier, complete with the coiled lengths of cable attached to Kimberly's electrodes. Not for long did we share in that occupation—necessity is the mother of invention—and we quickly resurrected our individual confidences to carry monitor and Kimberly simultaneously.

Carrying the monitor was a minor adjustment, but it served to highlight all the ways that were different from the experiences with our own children. As an example, when a parent speaks about the infant progeny, he speaks expansively about the physical and mental attributes of the new baby, and he will retell the tale to anyone who will stop long enough to listen. But who do you tell that your beautiful, ever-smiling, sweet-dispositioned child carries in her system the AIDS antibodies? We told those persons who needed to know: our rector and our children knew as soon as we made the decision to bring Kimberly home. We informed neighbors with children, and friends who were pregnant. We also shared the news with all our close friends, confident they would be supportive. Of course, there were those friends who joined us at the hospital for CPR and monitor training. God bless them. They have been the babysitters and the loaners of equipment.

Kimberly's coming to us was not all flowering fields and spring breezes. Our decision to have Kimberly has distanced us from a few friends: there are no more visits, there are no inquiries or only perfunctory questions about Kimberly (and then by telephone); and when pressed gently to "drop by," there are the ready responses for declining. Our prayers are for them that they may overcome their fears; and for us that we may be led to understand fears that turn people away from one of God's children.

The theme of visiting brings to mind the first visit after Kimberly came to live with us with her mother. This occurred a full month after Kimberly left the hospital. For the first planned meeting, her mother did not appear. Great aunt—the family matriarch—we were to discover later—came for the visit. What did she know? Only that the mother's addiction was the cause. And, she interjected, she would have come for that first visit had she known it was all right. The following week the mother did arrive, shoulder to shoulder with the great aunt. How they differed. The older woman's hands and heart reached out eagerly—hungrily—to embrace and to enfold Kimberly. The mother was tentative. She touched her child and drew away, offering no words of endearment.

And it was at that meeting or possibly the next one when I accepted that Kimberly would remain with us but for the short term only. I was brought to the realization after a period of four to six weeks that she was not our child to keep forever. When I think of this future separation from her, I am comforted by remembering an Army chaplain whom we knew years ago. At each baptism he conducted, he strode the aisles of the chapel introducing to each

parishioner the new Christian. And then he cautioned the parents that the infant he held was not theirs. The child was to be with them for a little while, on loan from God, to love and nurture, but always to live his own life as God's own idea and creation from the start.

To know Kimberly is to visit with her daily . . to start each day with her in silence. There are no infant demands for a dry diaper or belly-filling formula. We have all slept through the night. The transmitter in the baby's room and the receiver in our room are good sentries, but there are no alerts to sound. Not that we haven't had our moments of stark terror. The apnea monitor has sent out its piercing alarm. On that occasion, as one person, the two of us jammed the doorway, racing to Kimberly's room. Keystone Cops with tears. False signals were frequent. With experience, however, we learned to have monitors exchanged and learned the correct placement of the electrodes. We learned to discipline ourselves to detect her breathing while the alarm sounded at one second intervals (thereby verifying the need to exchange a machine). With the monitor quiet, the morning silence now has more meaning than the happy knowledge that Kimberly slept well.

Mama greets our baby in the morning, giving thanks for the new day. Kimberly stretches as she is rolled over on her back, opens her eyes and smiles—yes, she smiles. And we give thanks again to our Lord for this new day. And then it is "glove time." After the monitor is disconnected, Kimberly is readied for a change and that requires disposable gloves. They are about the only outward evidence that within that beautiful child's intricate systems there exist the AIDS antibodies. When first we brought Kimberly home, we were following 1984 guidelines advising the use of gloves while feeding. Within a month that practice was discontinued. (When we worked with AIDS patients initially four years ago we were cloaked in gowns, masks, gloves, hat and shoe covers. With these hygienic practices we were inadvertently contributing to the isolation which the patient was already sensing. Today, in almost all circumstances of care for AIDS patients, they can see compassionate eyes, a caring smile, and feel the touch of willing hands.)

Mama devotes her mornings to outside work. We are supported in this by the local government which provides a qualified care giver for Kimberly from Monday through Friday. The care giver is not our only official visitor or contact. A nurse comes weekly to evaluate Kimberly's progress. (Kimberly is thriving.) There are two hospitals monitoring her health. Social service workers evaluate us. They inspect us in our home. They coordinate the weekly visits—as to time and place—with Kimberly's relatives. We are now a less private family. But we are heartened by the extraordinary service being performed on behalf of a child unable to care for her own exceptional needs. This is a community service for which the taxpayer

is receiving a good return on investment. And we, the foster parents, are not forgotten in another aspect: training. For seven weeks, each Tuesday evening, we attended and participated in in-depth training to become certified foster parents. Kimberly joined the class and became the adored mascot of the group.

The weekly visit with the great aunt continues and often another relative comes with her, but seldom does Kimberly's biological mother make the meetings. When we first started, both Mama and I participated in these visits with Kimberly's family. Now that the visits are in the afternoon, Mama is going alone. The trepidation is less now, and great aunt is admired by both of us. She is raising her niece's other children. She was fearful of AIDS when Kimberly was first born and would not go near her. But she educated herself and now *I Corinthians* 13 speaks through her. Recently, the great aunt asked Mama if she could bring an outfit for Kimberly to wear on Sundays. And Mama, of course, said, "Yes, yes, yes."

Our weeks are punnctuated with moments such as this weekly visit with family, but the other hours are more routine: the laundry is a daily requirement as is the formula preparation. Nurturing. Not exactly poetry, but nevertheless the constant caring that depicts love never ending.

By late afternoon I am home, and we three share our time together. Because our days together are limited, they are precious. This is the time of day when Kimberly becomes very vocal, testing every octave and giving us her version of yodeling. And we linger over every moment we have together. We savor them.

At bedtime Mama says Kimberly's prayers. She prays that if it is God's will, Kimberly will be spared the AIDS virus. That her mother be helped to overcome her addiction, that her great aunt's strength and wisdom be sustained and that Kimberly grow up to love God and to be loved by those who also love and serve Him.

Now we have started taking Kimberly to Sunday church services. We explain, to those who ask, that Kimberly has family inherited medical problems. How will those parishioners react if Kimberly's health deteriorates? We know that we are not endangering them by this casual contact at the social hour. Nevertheless, how will those parishioners feel if Kimberly does become a person with AIDS? We don't know, but we judge that for now we shouldn't tell everyone about her status. We want to respect Kimberly's dignity and protect her by avoiding public announcement and the risk of generating a circus atmosphere.

And what do we look forward to? To lots more laughter—enjoying with Kimberly the thrill of discoveries, the pleasure of sounds, the silliness of tickling, the closeness of hugs and kisses. To satisfactions—of overcoming obstacles, meeting goals, developing

relationships. To routines—those kept and those interrupted, and to tears.

We will, we know, have to give Kimberly back. If she remains healthy, (and, oh, how we pray that she does!) we'll be asked to return her to her family. Then tears of gladness for her good health, and tears of sadness for the vacant place in our lives will flow mingled together. And we will hope that we'll be permitted to see her from time to time. If her health declines, and no cure for AIDS has been discovered, we will travel with her the length of her life's journey, and see her return to her Creator.

And we will remember the lessons we have learned. Babies are great teachers. Surely, those who proclaim self-righteously that AIDS is God's judgment against sinners would be hard pressed to justify their position as they look into the face of a child like Kimberly. We'll remember lessons in patience and obedience and we will remember our Lord's continued attention to Kimberly's needs and ours.

We will look forward to other babies who need a place to stay and hearts to love. And each child who comes to us will be a reminder that miraculously joyful moments occur and that our natural response to them is laughter.

# Neuropsychosocial Complications of HIV: Information and Interventions for Caregivers

**Susan M. Fair**

One has only to talk with someone experiencing symptoms related to human immunodeficiency virus (HIV) to recognize the tremendous physical and psychological impact of this virus and its related illnesses. Most persons are not prepared to deal with the reality of sickness and death in early adulthood. It is painful to see young people without the energy we expect of youth. It is difficult to talk with a young man or woman who may not see his or her children grow up. It is sad to talk about funeral arrangements instead of new careers and long-range life plans. And, it is hard to listen to and respond to the questions of why, why me, why now?

We are not surprised by the complicated and demanding psychological issues raised by the spectrum of HIV disease. We understand that the threat of fatal illness, physical illness itself, and issues related to dying, place immense stress on the psyche. These issues call upon all of a person's psychological resources to cope with the meaning and reality of such experiences. And, while we are now accustomed to hearing about various aspects of HIV and acquired immune deficiency syndrome (AIDS), to meet and talk with a person who is living with the diagnosis forces us into a more personal confrontation with the impact of this disease. Now, as more people have become ill with HIV disease, we recognize an additional aspect of the virus which presents a special problem both for those infected and for those providing care to them.

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For persons who develop HIV disease, clinical evidence suggests an increasing likelihood of the development of disease in the brain. Such disease processes appear to result from the direct action of HIV on the brain or they are secondary to illnesses resulting from immune system suppression. It has been reported that between 40% and 60% of the persons within whom AIDS develops will experience impaired neurologic functioning; clinical experience suggests that the numbers may even be higher (Levy, et al., 1985; Navia & Price, 1986). Thus, in addition to physical debilitation, infection with HIV and secondary illnesses can result in alterations in the functioning of the brain, causing changes in behaviors. This neuropsychological impairment, therefore, brings about changes in precisely those characteristics that help define each individual person. For it is through the integrated activity of the brain that meaning is attached to perception; that memories are formed, stored, and recalled; that emotion is modulated and elevated into consciousness; and that expressions of pleasure and need find words and actions. Disease processes that interfere with the functioning of the brain can result in tremendous losses for the individual and dramatic changes in the experience of the self. In addition, overt behavioral changes can occur, which may put the person at risk and create numerous problems for caregivers and families.

## Etiology and Symptoms

The immune system response of the human body is the primary source of protection against attack from foreign organisms. Very simply stated, HIV infects and destroys cells that are vital to the effective response of the immune system leaving the body susceptible to opportunistic infections and the development of malignancies (Abrams, 1986). It has also become clear that HIV is neurotropic, which means that it appears to have an affinity for cells in the central nervous system (the brain and spinal cord) and can infect and destroy them directly (Gallo, et al., 1984; Levy, et al., 1985). Occasionally this has been found to occur even before or without the signs of immune system deficiency more typical of HIV disease (Beckett, et al., 1987; Navia and Price, 1987). Both types of infection, that of the destruction of cells necessary for immune system response and that of cells in the nervous system, have implications for effective brain functioning, but in somewhat different ways.

When HIV alters effective immune system response, the body becomes vulnerable to the abnormal growth of tissue (neoplasms) and to "opportunistic" infections, so called because they need the opportunity of a weakened immune system if they are to cause illness. Neoplasms that occur in some patients with HIV infection include Kaposi's sarcoma, a cancer of the body's small blood vessels, and systemic and central nervous system (CNS) lymphomas.

Lymphomas are cancers of the lymph nodes which often spread to the CNS (Martelli, et al., 1987). Organisms that cause opportunistic infections include protozoa (*Pneumocystis carinii, Toxoplasma gondii*), fungi (*Candida albicans, Cryptococcus neoformans*), bacteria (Mycobacteriaum avium-intracellulare), and viruses (human cytomegalovirus (CMV), herpes simplex types 1 and 2) (Price, et al., 1986).

It is secondary to various infections and CNS lymphomas that brain functioning, and thus, behavior, can be altered. For example, *Toxoplasma gondii*, in persons with AIDS, causes abscesses in the brain. Such an abscess grows, destroying brain tissue and causing increased pressure in the brain. Symptoms may include seizures, high fevers, and declining alertness and attention (Martelli, et al., 1987). In the case of toxoplasmosis, treatment for this parasitic infection can result in the reduction of the abscess and a decrease in symptoms (Abrams, 1986; Price, et al., 1986). Other disease processes that can affect brain functioning include cryptococcal meningitis, CNS lymphomas, and encephalitis. Meningitis is an inflammation of the protective layers of tissue around the brain and typically causes symptoms of fever, headache, and decreased alertness (Perry & Jacobsen, 1986). Patients with CNS lymphoma may or may not show neurological changes before death (Perry & Jacobsen, 1986). Encephalitis, a general term referring to inflammation of the central nervous system can be the result of a variety of opportunistic infections including toxoplasmosis and herpes viruses. Symptoms can include seizures, paraparesis, hemiparesis, incontinence, mutism, and global dementia or coma (Perry & Jacobsen, 1986).

However, all of the above mentioned disorders have been found to account for less than one third of the cases that include CNS dysfunction in patients with HIV infection. The majority of patients who have HIV-related CNS complications appear to be suffering the effects of direct central nervous system infection with HIV. They may or may not show concomitant immune system suppression (Beckett, et. al., 1987) and may or may not develop neoplasms or opportunistic infections. This condition will be referred to here as "HIV dementia." Elsewhere it has been reported as "subacute encephalitis," "AIDS encephalopathy," "AIDS dementia," and "HIV dementia complex" (Navia & Price, 1986; Perry & Jacobsen, 1986; Snider, et al., 1983). The prevalence of this diagnosis has recently been acknowledged by the Centers for Disease Control (Center for Infectious Diseases, 1987). In fact, as of September 1, 1987, the mere presence of this symptom complex is sufficient for the diagnosis of AIDS.

The course of HIV dementia has been shown to vary in its rate of progression. In some patients the decline is rapid, occurring over a period of weeks. In others, it occurs more slowly, over months

(Navia & Price, 1986). Dementia is defined in the Revised Edition of the Diagnostic Statistical Manual of Mental Disorders (American Psychiatric Association, 1987) as characterized by "impairment in short and long-term memory, associated with impairment in abstract thinking, impaired judgment, other disturbances of higher cortical function, or personality change. The disturbance is severe enough to interfere significantly with work or usual social activities or relationships with others" (p. 103). Deficits of higher cortical functions include disorders of language, movement or motor functions, tactile recognition, and constructional abilities. Alterations in behavior and personality may also be noted.

In HIV dementia, the early symptoms often include memory loss (particularly recent memory, although loss of long-term memories has been noted), difficulty with concentration, mental slowing, and confusion (Price, et al., 1986; Price, et al., 1988). Persons in this stage of dementia may be misdiagnosed as depressed because they show apathy and social withdrawal. Less frequently, there may be agitation, acute confusion, and even hallucinations, although these symptoms are rare at this stage. Motorically, patients may have notable tremor, leg weakness, loss of coordination, and an unsteady gait (Price, et al., 1986).

For the majority of persons so affected, the course of the dementia is a steady decline from these early symptoms (Price, et al., 1986). There is a progressive loss of intellectual functions with more severe memory loss, impaired judgment, increasing distractibility, and more notable psychomotor slowing (slowed thought processes and movements). In the late stages of HIV dementia there is often loss of self-awareness and behavioral disinhibition resulting in socially inappropriate actions. There may also be organically based psychosis with both delusions and hallucinations. Also in the later stage there is typically significant weakness in legs and arms, generalized seizures, and periodic flexions or extensions of the body or extremities known as myoclonus. Incontinence of bladder and bowel is very common. Mutism and immobility result in the end stages; persons can survive in this state for several months, dying usually of a concurrent infection (Price, et al., 1986).

## Emotional Issues and Interventions

Emotional reactions to a diagnosis of HIV seropositivity, HIV-related disease, or AIDS, come in as many varieties as there are people. Each person generally reacts in a way that is consistent with his or her personality and typical style of coping with severe stress. However, two issues seem to present themselves at one time or another to almost all persons who are infected, regardless of their personal coping style. These issues, simply stated, are feelings of powerlessness and isolation. The nature of the disease, its fatality, the stigmatiza-

tion of those infected, and the fear of contagion, all make powerlessness and isolation very real concerns for most people who are infected and also for those who care about and treat them.

Complicating a person's emotional response to the diagnosis of HIV or AIDS is the fact that both the threat and experience of prolonged physical illness are stressful. Depression is common and each change in a person's physical status requires adaptation to a different level of functioning. The process of adaptation often involves experiencing anger and/or sadness at the new loss, followed by adjustment to new symptoms. Finally, the new physical status is accepted and integrated into the person's view of him or herself.

When the disease process interferes with the effective working of the brain, there are further complications. Alterations in psychological functioning are often directly connected to metabolic or structural changes in the central nervous system rather than primarily reflecting an emotional change or response. Given the predominance of HIV dementia as the primary underlying cause of neuropsychological problems in persons with HIV and AIDS, discussion in this section will focus on issues related to this particular disease process.

The onset of HIV dementia is typically insidious. Mild lapses in concentration and on occasions forgetfulness are often initially attributed to being over stressed or to depression. These lapses may be noticed by the affected person and initially dismissed, or the first awareness of the symptoms may come from others drawing attention to them. Friends and family may note the mild forgetfulness or be aware of slowing in the affected person's thinking (Price, et al., 1988). When the symptoms worsen to the point that they are acutely noticed by the affected person, the emotional response commonly involves concern, fear, and at times, disbelief. Psychological defenses are automatically called into action. Persons who typically minimize and deny will do this. Those who tend to become angry, will become angry. Depression is also commonly seen as the symptoms become more noticeable. The previously mentioned issues of powerlessness and isolation also become extremely relevant to virtually all persons experiencing a dementing illness. This may be true, in part, because the illness is invading the person's very source of awareness, perception, emotion, memory, and expression; functions that provide information vital for autonomous functioning and interpersonal connection. The decline and/or loss of these functions can be a tremendously frustrating and painful experience.

In addition to powerlessness, a dementing illness also brings its own kind of isolation. It can be very embarassing to forget someone's name, to lose track of a conversation, or to be unable to find the words to express oneself. In addition, frustration can run high in friends and family members who expect and want the affected person to behave in the ways he or she always has. This is especially difficult

when there are no observable signs of illness, and lapses of memory or concentration are easily interpreted as intentional or malicious manipulations. Social withdrawal is a common response to the embarassment and frustration of these problems. As dementia progresses, isolation occurs in other ways. Physical debilitation makes activity less possible, further distancing the affected person from others. As deterioration continues in the brain, there is reduced capacity for interaction with the world. With declining concentration and memory, there is loss of contact with one's own present and past; physiological deterioration deprives the person of the usual means of interaction and knowing. At a point in the dementing process, which appears to vary from person to person, there is loss of self-awareness that includes a loss of awareness of deficits in mental and physical functioning. We assume and hope that this loss of awareness provides emotional relief for the affected person. However, this can be a particularly difficult loss for family and friends, for it brings with it a more complete loss of the person they loved.

Interactions with the same person who has HIV dementia must be tailored to the specific person's needs and the stage of the illness. This requires that the helping professional be familiar with the disease process and understand the implications of the person's diagnosis. It also requires sensitive listening so the needs of the individual can be heard. Some will want to talk about what is happening to them and will request assistance and information, others will not. Even for those who decline assistance, it is critical that help and contact be offered in a sensitive and genuine manner. Some will see the onset of mental decline as the signal to begin finalizing personal business, others will avoid decisions about dying, wills, and funerals until they are too demented to make rational decisions and others will have to do it for them. Some will be acutely aware of their losses and others will not.

From the time of initial diagnosis of seropositivity to HIV, the affected person may question the fairness of his or her predicament and begin searching for understanding of why this has happened at this point in life. There is a powerful human need to find reasons and thereby reduce the tremendous sense of impotence. Self-blame often mingles with blame directed at others, particularly if the person can identify the source of their own infection. It is not uncommon for a person in this situation to wonder about the role of God in their life and in the larger human struggle against this deadly disease. Such wondering can occur whether or not a person previously had a strong religious affiliation. Feelings of betrayal or abandonment by God are not uncommon, as are feelings of anger at the injustice. This can also be a time when belief in God is strengthened and religious affiliation becomes an important source of comfort and hope. Questions about God and religion also arise relative to thinking about death. As a

person considers his or her own death, there can be a desire to settle things with God or to know more about dying and death. For a person with a dementing illness, there can be increased pressure to talk about and resolve these issues as the realization occurs that their body may, in a very real sense, live longer than their mind. Care givers who work with persons living with AIDS must be prepared to discuss and address these issues. Such preparation may involve a personal evaluation and confrontation of the very same issues for the care givers.

## Intervention

Intervention with a person suffering from an HIV-related illness requires sensitivity and the ability to join the person wherever they are in the process of adaptation to the diagnosis. It is important to provide a sense of safety for the expression of difficult questions and intense feelings. This is a challenge for all who provide services for persons with this disease. An additional challenge is the necessity of altering interventions to meet the restrictions presented by a decline in intellectual functioning. Early in the course of HIV dementia the mild symptoms of foregetfulness and poor concentration can be countered by helping the affected person to write things down, to establish routines, and by encouraging them to let others know if they need things repeated or need information presented more slowly. These can be difficult adaptations to make for the person who is not used to such strategies, but when implemented they can make life more comfortable.

It is in this early stage when the discrepancy between how a person looks and what they are capable of may be most noticeable. Since HIV dementia can be the initial and only evidence of HIV disease, some persons who are affected by it can appear physically healthy. They do not look like they should be forgetful or inattentive, and it is easy to misinterpret these problems as willful or manipulative. It can be extremely frustrating and hurtful to minimize or ignore the deficits of someone with brain impairment simply because they do not look like they should have such difficulty.

As the dementia progresses, interactions need to be further tailored to the person's intellectual limitations. It may become necessary to reintroduce oneself at each contact to aid failing memory. Briefer but more frequent contacts can minimize fatigue and increase daily routine, which is important in keeping dementing patients oriented. The use of simpler language in the form of less complex sentences or concepts may become necessary to maximize comprehension (Bocallari, 1987). If behavioral acting out occurs, such as wandering and becoming lost, or inappropriate social behavior such as genital exposure or public urination develops, limits need to be set for the protection of the affected person as well as others.

Such behavior can necessitate physical restraint, confinement, or psychiatric intervention in the form of medication. Interacting with a person in the final stages of dementia can be difficult because of the lack of responsiveness. Although a person may be conscious and alert, there may be little or no response to words or touch. We do not know the meaning of such contact for the severely demented person and the reasons to attempt contact at this point lie in our respect for human life and our hope that even, at this point, a touch or a word relieves isolation.

As dementia progresses, the focus of intervention for the caretaker often changes from the affected person to his or her family and friends. Interacting with and caring for a person with dementia is often a sad and tiring experience for all involved. Just as dementia robs the affected individual or his or her memories and usual means of connection with others, so it robs family and friends of the person they love. Family members and friends may grieve the loss of the person twice, once as the mind fades and again when the body dies. Patience, compassion, and acceptance of difficult questions and intense feelings are necessary for those providing support to survivors.

## What About the Care Giver?

Persons with HIV and related diseases are not the only ones prone to feelings of powerlessness and isolation. The same feelings can be found among care givers as well. Each person providing services to others with HIV disease or AIDS must cope with his or her emotional reactions to the work. We can expect our responses to this work to reflect and to be consistent with our own personal style of handling challenge and stress. This is difficult and rewarding work and to do it well we must be aware of its impact on our lives, particularly in terms of our emotional responses to those with whom we work. Care givers are not immune to feelings of anger, despair, frustration, and sadness, nor should they be. They need these feelings, as well as their determination, faith, hopefulness, and joy, if they are to understand and respond to the person who lives with HIV.

## Prejudice and Judgement

Another essential task for anyone who works with persons who have HIV infection or AIDS is an evaluation of one's thoughts and feelings about the most common forms of transmission of this disease and the implications that this may have about the lifestyles of those for whom they are providing services. Sex, promiscuity, bisexuality, homosexuality, and intravenous drug use are topics that spark intense feelings, heated discussion, and argument. They are topics about

which many people have strong opinions and judgments. Such opinions and judgments do not have to interfere with providing service to persons infected with HIV. However, they are very likely to interfere if they have not been honestly and directly addressed. Our unknown, unconsidered thoughts and feelings are the ones that are most likely to interfere in our work, resulting in avoidance, distancing, lack of empathy, and even error. Care givers must identify and acknowledge their feelings, judgments, and prejudices with the goal of responsible personal and professional management of such issues.

## The Treatment Team

The physical, psychological, spiritual, and social needs of the person with HIV infection or AIDS demand the expertise and involvement of many people. This is a special opportunity for members of many professions to work together in providing comprehensive services. The physical and emotional condition of a person with AIDS can change rapidly. Therefore, care givers need to be in contact with each other to monitor and meet the needs of the ill or dying person. It is also important that all care givers have contact with each other to share their own unique perspectives on the issues affecting those served and to keep themselves from personal and professional isolation.

## Conclusions

The challenges presented by the presence of HIV are many. They continue to increase as the number of affected persons grows. Although many people can still say that they have been personally untouched by this disease, its impact is growing harder to ignore. For those who are personally touched, by having the virus, seeing its effects on loved ones, or providing professional services to persons with HIV infection and AIDS, the challenges are even greater. The added problem of brain disease, which is now clearly recognized as one possible consequence of HIV infection, demands special consideration and adaptation of services. Persons who experience a decline in their ability to think efficiently, to concentrate, or to remember things experience loss as surely as those who experience a decline in physical functioning. Sensitivity, compassion, and thoughtfulness are essential for the caregiver who works with any person who has HIV disease. Impaired brain functioning in a client or patient also demands immense patience on the part of care givers. During the later stage of dementia, care givers must find ways to make contact with the patient and to keep him or her safe and comfortable. Ultimately, they must experience the loss of their client or patient. Although the challenges are great, the rewards are also tremendous,

for it becomes possible to see the tenacity and adaptability of the human spirit, the preciousness of life, and inevitability of death.


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# Look Around

**Jarvis Nathan**

Since about late 1979 and early 1980 we started looking at this disease called AIDS and the effect it's had on lives. It seemed to be contained in certain areas to high risk groups such as homosexual men, I/V drug users, etc.

AIDS, we have found, knows no color, age or sex and goes far in devastating the lives of all around it.

Attention focused on AIDs when actor Rock Hudson told his story, when Ryan White, a twelve year old school boy fought in court to go to school, and the Ray children of Florida were burned out of their home.

Men, women, children, elderly and mainstream America has now discovered that AIDS is among us. If AIDS is allowed to continue to spread at its present rate of growth, by 1991 everyone will know or be related to someone infected with the virus. To date there is no known cure or vaccine to fight AIDS. The only weapons we have are education, love and compassion.

We can educate ourselves with facts, not fears about this virus. AIDS is a sexually transmitted disease being passed by the exchange of body fluids carrying the virus (semen, vaginal secretions, blood). AIDS can also be transmitted through dirty needles used by I/V drug users and also by an infected mother giving it to an unborn child.

There was a possibility of transmitting AIDS by blood transfusions but since 1985 a screening process has made blood supplies safer. Donating blood is not a means of transmission because the equipment used is sterile.

Casual contact is not a means of transmitting—shaking hands, hugging, using eating utensils or rest rooms, or even living with and caring for AIDS patients is not a risk. There are precautions to be taken when handling body fluids of an infected person, but these

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SFC Jarvis Nathan, U.S. Army, Ret., is a person with AIDS.

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precautions should be used with everyone because of many other serious diseases which can be transmitted in the same manner, and because of the lack of knowledge as to who is infected with whatever.

You cannot get AIDS from drinking glasses, touching or through insect bites. Rumors are spreading faster than AIDS. Outside the human body this virus is a wimp. We've come a long way with research, drugs and understanding about AIDS. This is a disease you have to work at to get.

It is risky to use the same toothbrushes or razors which may contain fluids or residue. Deep kissing is also risky because the virus can gain access to the bloodstream through open sores or irritations.

The effect AIDS has on lives is devastating. AIDS victims sometimes lose close friends, family, jobs, homes, and the list goes on and one due to prejudices and unfounded fears. At the same time they have to deal with the loss of health, weight and death. People fear them, and then they fear people, and so on.

Health care workers, doctors, families and friends who have shown love, concern and care have brought back light into otherwise dark lives. Many of the pictures we've seen of AIDS patients have only been of the patients who were dying or dead. There are so many who are healthy enough to work and carry on with their lives.

People must learn the ways this disease is transmitted and how not to get it. They must also learn that they can safely interact with infected persons without getting it.

We must teach people about lifestyles, teach them how to change them if necessary. Decide if a lifestyle is really what you want, or change it and live.

Kids are today saying no to drugs—sex should be added to that list. Once they become old enough to understand what's really happening and the dangers then, armed with knowledge, they can make a sound, responsible decision about their own lives and futures as affected by sexual activity.

By 1991 a quarter of a million people will be dead from AIDS and others will be infected. Education, facts and a kind word or smile are all available to us—use them to protect yourself and to strengthen someone else.

The day will come when some man or woman will stand and receive the Nobel Prize for finding a cure for AIDS. Many others will go unthanked—nurses, doctors, families and friends who give of themselves to fight the pain. Let's not forget them.

Today is a good day to learn about AIDS and to tell someone you know. We can save lives, ease pain, fight ignorance and bring hope.

# My Existence With The AIDS Virus

**An AIDS Patient**

Most people oppose being tested for the HIV or AIDS virus. Why? Because the media has instilled a fear in the minds of everyone about the illness and the people who are infected with the disease. What most people don't realize is they have no reason to fear those who have AIDS or have been tested positive for the HIV virus. At least they know who have been infected with the virus or the disease; but what about those who have not been tested. Is there any way, just by looking, to tell who has the virus?

The fear that is getting to most who have been tested positive for the virus or have AIDS is rejection. One does not want to be rejected by family, friends, or society in general. Being rejected takes a greater toll on the body of those affected with the disease because it leads to stress. Too much stress can have a devastating affect on the system. I was glad to have been tested and found out in time that the virus was in my system. After being told that I had tested positive for the virus, I did not think about being rejected. I was embarrassed because over one hundred seventy-five persons were tested for the virus, and I was the only one to come up positive.

I went home, sat, appraised my life and tried to cry. For some unknown reason, I could not cry. However, after sitting and thinking about why I could not cry, I realized that I was angry with myself for having contracted the virus. I was not angry with God or anyone else for my situation. I felt that I should have been more careful with my life, but I was not.

My next thought was: "How do I feel about myself and is there any medical help available?" After appraising my life and accomplishments, I felt good about myself. Since I felt good about

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The author of this statement is an Army Staff Sergeant on active duty who is HIV-positive. He is presently a patient at Walter Reed Army Medical Center in Washington, D.C.

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myself, I decided to live the rest of my life one-day-at-a-time. I felt that I was very lucky because the virus had not gone through my body as it had done others. I then prayed and thanked God for what He had given me and asked for His guidance while living the rest of my days. I feel very positive about many things and believe that positive thinking and belief in God have been a major factor in my life. I have found no reason for ending my life but live it to the fullest.

So, what do I do now? At the present time I am planning the rest of my life because I have no idea how long I will live with the virus or whether a cure will ever be found. I am grateful for what I have. My desire and hope are to help others who are fighting with the virus, with God's help. There are people who are not handling the situation, having the virus in their system, very well. There are many who have chosen to accept the fact that they have a killer virus in their body and plan to go on living. But, there are those who have chosen to commit suicide, drink heavily, or even turn to the further use of drugs. Most of these people don't realize that they are inflicting more harm to themselves. By turning to drugs and alcohol, these people are lessening the chances of their system for fighting diseases and infections. As for me, I am going to pray and live life as I am blessed. As one writer says, "Life is what you make it and what you make it is up to you." So I plan, with God's help, to make the best of the time I have left.

# AIDS: Process, Content And Amnesia

**Robert H. Gemmill**

Early in 1985 the Social Work Service at Walter Reed Army Medical Center initiated a broad range of social work services for a small number of AIDS patients and their family members. Initial services included: evaluation for psychosocial adjustment and functioning; discharge planning; resource identification and referral; individual, child and family counseling; health maintenance education; tracking of medical boards; command consultations and coordination and integration of military and civilian health care services. These services were a natural extension of health care intervention procedures already provided to both inpatients and outpatients with other medical diagnoses.*

As the number of active duty soldiers and family members with HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) increased, coupled with the impending testing of all active duty soldiers for the AIDS virus, it was obvious that there would be an increased demand for inpatient and outpatient social work services.

The exact administrative and clinical scope of this increased demand was uncertain. Therefore, the Social Work Service formulated two seemingly simple questions: "What are the social work

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methodological intervention procedures that will be needed to provide a fullrange of services to HIV/AIDS patients and their family members?" and "What psychosocial information exists in the professional literature that can assist with program design, treatment and evaluation?" The first question was targeted at identifying the "process" of the social work profession while the second question sought to secure "content" or substantive information required for problem resolution.

## Problems

Two problems were encountered while trying to answer the two questions. First, although there was already an established social work process, it was temporarily forgotten at the time it was needed the most to develop "content" material. (The definition of "process" and "content" is provided in the section entitled, "twelve immunizing content principles.") This resulted in a natural attempt to discover or find the "social work process" by formulating a question that initiated a time consuming quest for the elusive process. Interestingly, other health care professionals were doing the same thing at the same time. We identified this phenomenon as "process amnesia."

Process amnesia immobilized or denied access to the social work process and methodology. The symptoms of this amnesia seem to be an acute inability to draw upon an established professional process. Coupled with this inability is a tendency to perseverate on identifying or discovering the unknown process usually at the expense of not formulating or even considering "content" material.

Only after the cause of "process amnesia" had been successfully identified and resolved did twelve administrative/clinical "content" principles emerge through the rediscovered social work process.

A review of the literature was conducted to answer the second question which pertained to surveying the psychosocial literature. The second problem was discovering and retrieving a disappointing number of articles which addressed the psychosocial dimensions of HIV/AIDS. Without an inventory of professional literature to draw upon, health care professionals are denied a repertoire of research material to be utilized in constructing programs, developing services and evaluating existing and planned services. Therefore, the lack of professional articles presented a serious problem. The standards of practice, quality assurance and risk management procedures of a treatment program become suspect if the only standards utilized in program design, treatment intervention and evaluation are self-generated.

## Purpose

The purpose of this article is twofold: to discuss twelve "content" principles which are essential to consider prior to establishing a

HIV/AIDS program encompassing clinical services to patients and family members, (The twelve content principles, which help immunize against administrative and clinical program pitfalls, emerged from the encounter with and successful resolution of "process amnesia,") and to present a condensed version of the psychosocial literature on HIV/AIDS in a table format. The psychosocial literature includes articles which address the psychosocial-emotional-spiritual components or dimensions of HIV/AIDS to include psychosocial intervention techniques.

## Twelve Immunizing Content Principles

The Social Work Service developed twelve administrative and clinical "content" principles which gave substance and direction to the Social Work HIV/AIDS program. These principles also helped to immunize against program design and clinical errors.

The twelve content principles are similar to premarital therapy in that they offer an invaluable opportunity to critically look at a number of program design and treatment issues prior to commiting resources.

## Twelve Content Principles:

1. *Full access to services and equal treatment.* Individuals infected with the AIDS virus are human beings who are experiencing a disease process and should be afforded the same access to available hospital services and treated as any other patient within the confines dictated by their medical regimen. They deserve to receive the same high quality continuous health care as other patients and deserve to be treated with dignity, respect, and courtesy. They must not be discriminated against due to their medical diagnosis.

2. *Distinction between the State of HIV and the Process of HIV.* Unlike many other infections, being infected with HIV cannot be simply described as either being sick or being well. The infection is a process, which ranges from no symptoms to opportunistic life threatening infections, from mild psychosocial symptoms to overpowering life threatening catastrophes and tragedies. The disease is a process; and at each stage of the disease, the patient reacts physically, mentally and emotionally in different ways. A variety of intervention procedures are required during the entire disease process.

3. *Treatment and cure.* A cure is a procedure that restores health or makes one well. A treatment is a systematic process of care that may or may not result in a cure. Unfortunately, the popular and even the professional literature does not always make a precise distinction between these two terms, which can give the impression that since there is presently no cure for AIDS there is also no treatment for

AIDS. There are number of diseases with no cures, but there is always a repertoire of treatment modalities or strategies available to the practitioner and to the patient. Available treatment strategies for HIV/AIDS include: medical treatment for infections, psychotrophic medications for neuropsychiatric symptoms, prophylactic treatment, nutritional support, nursing intervention, safe sex education, adherence to a healthy life style, spiritual intervention and a whole host of psycho-social-emotional intervention strategies which are identified in the next section of the article, "Categorical Review of the Literature."

4. *Process and content.* Process refers to the methodology or the way a profession organizes or orchestrates its behavior to cope with problems. Process is an established and understood methodological procedure which is utilized by a profession to resolve an identified problem. Content is the substance, problem or topic of concern which is usually not well understood and is in need of a resolution. Both process and content are essential for complete problem resolution.

5. *Pride and prejudice.* Professionals take pride in being objective and in avoiding practices which are discriminatory. Yet, there are specific circumstances that have a great potential for raising myths, prejudices and stereotypes which can then find their way into policies, programs and treatment interventions. HIV/AIDS is such a circumstance. It is important therefore to be sensitive to prejudicial feelings when establishing policy, designing programs, and establishing treatment strategies so that such feelings do not become established administrative and clinical realities.

6. *Rehabilitation and debilitation.* Rehabilitation deals with restoring or re-establishing previous conditions as closely as possible. Debilitation refers to being weak, not strong, feeble, not able to care for the self. Rehabilitation is superior to debilitation. Programs and services should be directed toward rehabilitating individuals, not toward supporting or encouraging their debilitation.

7. *Multidisciplinary approach.* No one professional group can provide all the required services to individuals infected with HIV/AIDS or to their families. Therefore a multidisciplinary approach is essential if effective, efficient, and comprehensive services are to be available to both patients and family members.

8. *Practice and research.* A successful program is dependent upon the unification or merging of practice and research. Research integrates and orchestrates identified problems with available intervention strategies. While program designers, managers and clinicians may have access to resources and may be motivated to develop and

implement treatment program, without access to a "critical mass" of research information there is no clear or objective way to give direction to those resources and motivations. A good impulse does not insure a good program.

9. *Paternalism and self-determination.* The medical environment is predisposed to expect and even demand at times that individuals transform into patients and assume the sick role.[1] This usually asks the patient to conform and to comply with medical treatment and advice. Yet many individuals infected with the AIDS virus are not debilitated. They are in good or excellent health both physically and mentally. They are able to function productively in society as independent and responsible adults making their own decisions. These individuals are not ready to assume the patient role and do not need to sacrifice their independence for medical treatment.

It may be a prudent treatment approach to solicit the help of the patient in the treatment program. It has been the author's experience that patients want to talk about their own issues, desperately want to participate in their treatment, want to discuss treatment options, medication side effects and want to clarify what psychosocial issues they are experiencing rather than to be told what they should be experiencing or must be denying.

10. *Content and Context.* Content refers to a specific subject matter while context refers to the matrix or environment in which the content material takes place. Content is therefore influenced by the history, culture and the entire social organization. Since context gives meaning to content it is essential that an attempt be initiated to understand the contextual structure that surrounds HIV/AIDS in our society. Not to understand the contextual envelope which HIV/AIDS resides within is to be denied the ability to predict, prevent and cope with reactions to HIV/AIDS.

11. *Affect and Cognition.* There are different ways to understand and respond to problems. Both affect and recognition are effective tools that can offer understanding to complex psychosocial problems such as HIV/AIDS.

12. *Technology and Compassion.* Often these two terms become polarized with one favored over the other. Usually technology is the favored child. If compassion is selected over technology, it is often accompanied by justifications and personal embarrassment. This is a

[1] T. Parson, *The Social System* (New York: The Free Press, 1951); Parsons, "Definitions of Health and Illness in the Light of American Values and Social Structure," in E. G. Jaco, Ed. *Patients, Physicians, and Illness* (Glencoe, Ill.: The Free Press, 1958); Parsons, "The Sick Role and the Role of the Physician Reconsidered," *Milbank Memorial Fund Quarterly* 53 (1975): 257-78; and A. C. Twaddle, *Sickness Behavior and the Sick Role* (Cambridge, Mass.: Schenkman Publishing Co., 1979).

sad state, for no matter which choice is selected by the clinician the patient loses.

A forced choice splits an effective treatment procedure into two incomplete parts. The importance of having both the technological and the compassionate aspects of treatment unified is well presented in a popular book entitled, *Love, Medicine and Miracles* by Dr. Bernie Siegel. Dr. Sigel makes an appealing case that both compassion for patients and the application of medical technology are effective and essential components of the healing process.

## Categorical Review of the Psychosocial Literature

The problem that interfered with answering the second question: "What psychosocial information exists in the professional literature that can assist with program design, treatment and evaluation?" was the unavailability of professional articles. To help resolve this problem the Social Work Service initiated a HIV/AIDS psychosocial clearinghouse. The purpose of the clearinghouse was initially to collect and store psychosocial articles to be used in developing and evaluating a Social Work HIV/AIDS program. As the clearinghouse matured, and as it was discovered by other military and civilian professionals, the function of the clearinghouse expanded to include the distribution of the centralized list of psychosocial HIV/AIDS articles to interested professionals.

Rather than simply to provide the reader with an alphabetical list of psychosocial articles, the following categorical review of HIV/AIDS psychosocial articles is extracted from the clearinghouse. The literature is arranged in a table format, rather than in an extensive and cumbersome narrative format, to provide a simple and readily accessible device for presenting and updating the contents of the professional literature. Some articles naturally overlap categories; therefore, they appear more than once. There has been no attempt to provide an exhaustive review of the literature, although the clearinghouse and the categorical review of the literature is updated quarterly. A copy can be obtained from the author.

The following format divides the psychosocial literature into four categories. Under each category words or phrases identify a subject discussed in the literature, the name of the author who wrote the article, and a number which identifies the article in the reference list located at the end of this article.

## The four categories are:

1. *Problem identification.* This section contains the literature which describes the overall problems associated with the HIV infection.

2. *Pre-policy philosophical issues.* This section contains articles which address issues for consideration prior to program design and implementation.

3. *Policy issues or need for policy information.* This section identifies articles which address either the appeal for a specific policy or describe an existing policy.

4. *Program needs and examples of established programs.* This is the largest section and contains articles which address specific psychosocial aspects of HIV/AIDS, usually clinical issues, which require remediation or resolution. This section is sub-divided into two parts: onset-impact-psychoneuroimmunology and psychological change articles and treatment strategies.

Onset-impact-psychoneuroimmunology articles address the psychosocial issues involved in HIV/AIDS or the impact these issues have upon individuals who are infected with the virus. The subjects of the articles are usually gay men. As noted by Dreher [2] the psychological variables in these studies include pre-existing trait characteristics, gay lifestyle stressors, identity issues and stresses resulting from the AIDs epidemic. Many of the studies employ the concept of psychoneuroimmunology which speaks to the relationship among psychological factors, neurological mediators and immune status.

Psychological change articles identify the modification or changes faced in the lives of those infected and may also address intervention techniques. Dreher notes that these studies target social support systems, coping style and clinical measures of mental status, such as depression and neuropsychiatric manifestations. Treatment strategy articles describe intervention strategies, both for the patient and staff, which can be employed to ameliorate psychosocial symptoms associated with HIV. Included in this section are articles that address implementation of psychosocial programs for individuals infected with HIV.

## CATEGORIAL REVIEW OF THE HIV PSYCHO-SOCIAL LITERATURE

### PROBLEM IDENTIFICATION

| | *Subject* | *Author/s* | *Reference* |
|---|---|---|---|
| 1. | AIDS and dialysis | Favero | 73 |
| | | Humphreys | 75 |
| | | O'Connor | 52 |

[2] Henry Dreher, "The Psychosocial Aspects of AIDS: A Workshop of the Institute for the Advancement of Health," Harrison Conference Center, Glencove, N.Y., December 1984.

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| | Pristave & Riley | 72 |
| | Schoenfeld | 74 |
| 2. AIDS and long term care | *AHA* | 24 |
| 3. AIDS and substance abuse | Caputo | 50 |
| 4. AIDS as a means to suicide | Frances, Wikstrom & Alcena | 68 |
| 5. AIDS hysteria | Korck | 55 |
| 6. AIDS in the workplace | Ryan | 23 |
| 7. Children with AIDS | Rogers | 80 |
| (AIDS and human services) | O'Hare Stangler | 20 |
| (Child welfare issues) | Anderson | 54 |
| 8. Confidentiality | Silverman & Silverman | 47 |
| 9. Countertransference issues | Perry & Jacobsen | 10 |
| 10. Countertransference issues | Dunkel & Hatfield | 12 |
| Anger | | |
| Denial of helplessness | | |
| Fear of dying and death | | |
| Fear or contagion | | |
| Fear of homosexuality | | |
| Fear of the unknown | | |
| Need for professional omnipotence | | |
| Overidentification | | |
| 11. Doctors counseling patients about sexual practices | Wiebe | 19 |
| 12. Epidemiology | Bennett | 25 |
| | Christ & Wiener | 8 |
| | Dowdle | 21 |
| | Furstenberg & Olson | 53 |
| | Public Health Service Plan | 15 |
| | Skeen | 16 |
| 13. Caregiver's stigma | Feinblum | 79 |
| 14. Health insurance | | |
| Blue Cross, Blue Shield | | |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| HMOs | Shahoda | 13 |
| MEDICAID | | |
| Risk pools | | |
| 15. Health professionals reactions | Morin & Batchelor | 65 |
| | Rosse | 69 |
| 16. Hospital issues | Burda & Powills | 76 |
| Blood screening | | |
| Cost | | |
| Isolation of patients | | |
| Legal issues | | |
| Worried staff | | |
| 17. Homophobia | Deuchar | 60 |
| | Dunkel & Hatfield | 12 |
| | Gramick | 49 |
| | Herek | 45 |
| | Langone | 34 |
| | Wiebe | 19 |
| 18. Homosexual's openess with health providers | Dardick & Gardy | 51 |
| 19. Homosexual promiscuity | Meredith | 71 |
| 20. Image of health care: God like figures that can heal everybody | Wiebe | 19 |
| 21. Impact on health care workers | Simmons-Alling | 44 |
| Anxiety | | |
| Isolation | | |
| Drain | | |
| Stress | | |
| 22. Journalism | Diamond & Bellitto | 27 |
| Ambivalent attitudes | | |
| Contradictory practices | | |
| Euphemisms | | |
| Misunderstandings | | |
| 23. Legislative proposals enacted or considered | O'Hare & Stangler | 20 |
| 24. Patient management difficulties | Perry & Tross | 64 |
| 25. Public Health Service's Response | U.S. Congress | 35 |

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 26. | Psychosocial methodological research problems | Joseph, Emmons, et. al | 56 |
| 27. | Reluctance to seek treatment | Martin | 18 |
| 28. | School issues | Black | 86 |
| | | NEA | 87 |
| | | Price | 88 |
| 29. | Sexuality and death | Wiebe | 19 |
| 30. | Social dimension of AIDS | Siegal | 30 |
| 31. | Society's outcasts | Wiebe | 19 |
| 32. | Staff hysteria | Burda & Powills | 76 |
| | | *Hospitals* | 14 |
| | | Wiebe | 19 |
| 33. | Stigma of AIDS | Martin | 18 |
| | | Wiebe | 19 |
| 34. | Threat to Blacks | Martin | 18 |
| 35. | Worried well | Morin & Batchelor | 65 |

PRE-POLICY PHILOSOPHICAL ISSUES

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 1. | AIDS depressing, but treatment environment nondepressing | Wiebe | 19 |
| 2. | Avoid simplistic solutions | Cassens | 38 |
| 3. | Emotional Involvement of staff<br>Acceptance<br>Nonjudgmental attitude<br>Objectivity | Simmons-Alling | 44 |
| 4. | Keep patients active pending test results | Scott | 32 |
| 5. | Know facts before make public statements | Wiebe | 19 |
| 6. | Open visiting vs. restriction of visitors | *AHA* | 24 |
| 7. | Patient control over diagnostic workup and treatment | Furstenberg & Olson | 53 |

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 8. | Patients want to be recognized and listened to | Wiebe | 19 |
| 9. | Professional have obligation to educate and to be role models | Wiebe | 19 |
| 10. | Professional staff need education on how to deal with issues of sexuality | Wiebe | 19 |
| 11. | Replace unhealthy with health coping behaviors | Durham & Hatcher | 33 |
| 12. | Respect patient's need for privacy and confidentiality | Durham & Hatcher | 33 |
| 13. | Sensitivity and respect for the needs of all communities | Cassens | 38 |
| 14. | Treat patients who have a fatal disease, not treat patients as embodiment of issues central to the AIDS controversy | Wiebe | 19 |
| 15. | Voluntary reporting, not manditory reporting of AIDS cases | Brandt | 17 |
| 16. | Walter Reed Social Work Service pre-policy components | Gemmill | 3 |

POLICY ISSUES OR NEED FOR POLICY STATEMENT

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 1. | Catholic Charities AIDS resolution | Strange | 77 |
| 2. | Development of patient care and health care needs | Public Health Service Plan | 15 |
| 3. | Health policy<br>Detection<br>Funding<br>Public information<br>Responsiveness<br>Role of health services<br>Surveillance | Brandt | 17 |

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 4. | Information and education directed toward target groups | Public Health Service Plan | 15 |
| 5. | Prevention of IV drug abuse transmission | Public Health Service Plan | 15 |
| 6. | Prevention of sexual transmission | Public Health Service Plan | 15 |
| 7. | Prevention of transmissibility by blood and blood products | Public Health Service Plan | 15 |
| 8. | Public health control measures | Public Health Service Plan | 15 |
| 9. | Office of the Army Surgeon General and Health Services Command policy toward HTLV-III/LAV | OTSG<br>HSC | 5<br>6 |
| 10. | Veterans Administration (VA) AIDS policy | Cohr | 81 |

## PROGRAM NEEDS (PSYCHO-SOCIAL VARIABLES) AND TREATMENT STRATEGIES TO INCLUDE IMPLEMENTATION PROCEDURES

### Psychosocial Variables: Articles on Onset-Impact Psychoneuroimmunology and Psychological Change

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 1. | Abandonment | Martin | 18 |
| 2. | Acceptance | Forstein | 57 |
| | | Nichols | 36 |
| 3. | Anger, unspecified | Dilley, Ochitill, Perl Volberding | 61 |
| | | Holland & Tross | 37 |
| | | Skeen | 16 |
| 40 | Anger, specified | Feinblum | 79 |
| | Discriminatory treatment | Newmark | |
| | Societal treatment | | |
| 5. | Anxiety, unspecified | Skeen | 16 |
| 6. | Anxiety about developing infections | Newmark | 40 |
| 7. | Anxiety about reactions of others | Miller & Green | 28 |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| 8. Catastrophic loss | Rubinow | 42 |
| 9. Confidentiality concerns | Cassens | 38 |
| 10. Dementia | Navia & Price | 29 |
| 11. Denial | Feinblum | 79 |
| | Forstein | 57 |
| | Nichols | 36 |
| 12. Diagnosis shock | Miller & Green | 28 |
| 13. Disenfranchisement as human beings | Rubinow | 42 |
| 14. Disclosure of sexual orientation | Cassens | 38 |
| 15. Depression | Dilley, Ochitill, Perl Volberding | 61 |
| | *Emergency Medicine* | 62 |
| | Holland & Tross | 37 |
| | Martin | 18 |
| | Miller & Green | 28 |
| | Perry & Jacobsen | 10 |
| | Perry & Tross | 64 |
| | Skeen | 16 |
| 16. Emotional reactions | Christ & Wiener | 8 |
| Fear of death | Christ, Wiener & | 31 |
| Fear of debilitation | Moynihan | |
| Fear of disfigurement | | |
| Fear of infection | | |
| Fear of social abandonment | | |
| Guilt about past sexual behaviors | | |
| Families emotional problems (anger, anxiety, blame, fear) | | |
| 17. Encephalopathy | Holland & Tross | 37 |
| 18. Family rejection | Cassens | 38 |
| 19. Fear of | | |
| Death | Christ & Wiener | 8 |
| Debilitation | Christ & Wiener | 8 |
| Desertion | Miller & Green | 28 |
| Disfigurement | Christ & Wiener | 8 |
| Dying | Wiebe | 19 |
| Infecting others | Miller & Green | 28 |
| Infections | Christ & Wiener | 8 |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| Pain and discomfort | Miller & Green | 28 |
| | Newmark | 40 |
| Social abandonment | Christ & Wiener | 8 |
| 20. Guilt and shame | Cassens | 38 |
| | Rubinow | 42 |
| | Siegel | 30 |
| 21. Hopelessness | Martin | 18 |
| 22. Illness as retribution | Dilley, Ochitill, Perl & Volberding | 61 |
| 23. Impact of AIDS on | Rubinow | 42 |
| Health care workers | | |
| High-risk groups | | |
| Public | | |
| 24. Impact on families | *AHA* | 24 |
| 25. Isolation | Cassens | 38 |
| | Dilley, Ochitill, Perl & Volberding | 61 |
| | *Emergency Medicine* | 62 |
| | Feinblum | 79 |
| | Howes | 43 |
| | Siegel | 30 |
| 26. Loss of | Durham & Hatcher | 33 |
| Assistance from caregivers | | |
| Control of body functions | | |
| Friends | | |
| Health | | |
| Interaction patterns | | |
| Life | | |
| Possessions | | |
| Privacy | | |
| Role | | |
| Self-esteem | | |
| Self-image | | |
| Sexual functioning | | |
| Status | | |
| 27. Loss of job | Newmark | 40 |
| 28. Neurological complications | Perry & Jacobsen | 10 |
| | Snider, Simpson, et. al | 11 |
| 29. Neuropsychiatric impairment | Loewenstein & Sharfstein | 26 |
| | Perry & Tross | 64 |
| Delirium | | |
| Dementia | | |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| 30. Neuropsychiatric manifestations | Perry & Jacobsen | 10 |
| Acute psychosis | | |
| Depression | | |
| 31. Neuropsychiatric complications | *Emergency Medicine* | 62 |
| | Perry & Tross | 64 |
| Anxious | | |
| Depression | | |
| Lethargic | | |
| Withdrawn | | |
| 32. Occupational disruption | Miller & Green | 28 |
| 33. Powerlessness | Furstenberg & Olson | 53 |
| | Holland & Tross | 37 |
| | Howes | 43 |
| | Miller & Green | 28 |
| 34. Psychiatric diagnosis | Holland & Tross | 37 |
| Adjustment disorder | | |
| Delirium | | |
| Dementia | | |
| Major depression | | |
| Previous psychiatric illness or personality disorder | | |
| Treatment-related side effects | | |
| 35. Psychological distress | Holland & Tross | 37 |
| Anxiety | | |
| Anger | | |
| Depression | | |
| Isolation | | |
| Reduced support | | |
| 36. Reduced | Miller & Green | 28 |
| Cognitive functioning | | |
| Physical functioning | | |
| Sexual functioning | | |
| 37. Response of medical staff | Holland & Tross | 37 |
| 38. Response to diagnosis of AIDS | Forstein | 57 |
| Shock, numbness, disbelief | | |
| Denial | | |
| Breakdown of denial | | |
| Acceptance | | |

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 39. | Situational distress<br>Denial<br>Anger, guilt, self-pity<br>Withdrawal<br>Acceptance | Nichols | 36 |
| 40. | Social disruption | Miller & Green | 28 |
| 41. | Uncertainity about illness and treatment | Dilley, Ochitill, Perl & Volberding | 61 |
| 42. | Unfinished business of patient | Dilley, Ochitill, Perl & Volberding | 61 |

*Treatment Strategies and Implementation Procedures*

| | *Subject* | *Author's* | *Reference* |
|---|---|---|---|
| 1. | Administrative perspectives<br>Planning<br>Organizing<br>Directing<br>Controlling | Calliari | 39 |
| 2. | AIDS and substance abuse<br>Advocate<br>Educate<br>Enable<br>Mediate<br>Social broker | Caputo | 50 |
| 3. | Art Therapy | David & Sageman | 85 |
| 4. | BankAmerica's policy on AIDS | *Ideal & Trends*<br>Ryan | 48<br>23 |
| 5. | Crisis intervention programs | *Emergency Medicine* | 62 |
| 6. | Crisis management: Seven steps | Goulden, Todd, Hay & Dykes | 63 |
| 7. | Discharge planning | *AHA*<br>O'Neil | 24<br>59 |
| 8. | Education | Deuchar | 60 |
| 9. | Emergency evaluation and management | Skeen | 16 |
| 10. | Family Service Center (FSC)<br>Orlando Counseling Program | Scott | 32 |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| 11. Federal, state, county and city program for AIDS<br>Advocacy<br>Emergency food<br>Food stamps<br>Housing<br>Legal benefits<br>MEDICAID<br>MEDICARE<br>National Institutes of Health<br>Social security<br>SSI<br>VA benefits | AIDS Action Council | 46 |
| 12. Financial support and housing | *Emergency Medicine* | 62 |
| 13. Gay Men's Health Crisis (GMHC) | Feinblum | 79 |
| | Lopez & Getzel | 66 |
| San Francisco (comprehensive service approach) | Nichols | 67 |
| 14. Group therapy for | *Emergency Medicine* | 62 |
| 4 isolation | Piotroski | |
| 15. Group therapy for | | 40 |
| support | Newmark | 4 |
| (National Institutes of Health) | Piotroski | |
| (Walter Reed Army Med. Cent.) | | |
| 16. Health professionals interaction with homosexuals | Dardick & Grady | 51 |
| 17. Hemophilia Patient/Family Model: AIDS and Hemophilia Module | National Hemophilia Foundation | 9 |
| 18. Home-nursing course for family, friends and lovers of AIDS victums | *Emergency Medicine* | 62 |
| 19. Hospice | Adkins | 83 |
| | Corr | 84 |
| | Kutzen | 82 |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| 20. Human Service Administrators response to: Children with AIDS, fearful parents implementation of policies and procedures for children with AIDS | O'Hara & Stangler | 20 |
| 21. Inpatient therapeutic milieu | Poland, Hellerstein & Amchin | 58 |
| 22. Legal assistance | Forstein | 57 |
| 23. Management guidelines | Holland & Tross | 37 |
| 24. Management of neuropsychiatric disorders | Perry & Jacobsen | 10 |
| 25. MEDICAID | Luehrs, Orlebeke & Merlis | 22 |
| 26. Memorial | Christ & Wiener | 8 |
| Sloan-Kettering Cancer Center Program | Christ, Wiener & Moynihan | 31 |
| 27. Ministering to the dying | Strange | 77 |
| 28. Nursing neurological assessment, diagnosis and care (National Institutes of Health) | Sunder | 41 |
| 29. Nursing response to powerlessness and social isolation (National Institutes of Health) | Howes | 43 |
| 30. Nursing psycho-social intervention approach | Durham & Hatcher | 33 |
| 31. Pastoral Care | Acheson | 89 |
| | Doubleday | 90 |
| | Hochstein | 91 |
| | Quinn | 92 |
| 32. Psychiatric assistance | Nichols | 67 |
| 33. Psychiatric intervention and psychotherapeutic process | Deuchar | 60 |
| 34. Psychiatric intervention recommendations | Perry & Tross | 64 |

| *Subject* | *Author's* | *Reference* |
|---|---|---|
| 35. Psychological treatment strategies | Forstein | 57 |
| 36. Psychoneuroimmunology | Ader | 78 |
| | Coates, Temoshok & Mandel | 1 |
| | Dreher | 7 |
| 37. San Francisco Generals' AIDS ward model | Wiebe | 19 |
| 38. Shanti volunteer project. | *Emergency Medicine* | 62 |
| San Francisco | Lopez & Getzel | 66 |
| | Morin & Batchelor | 65 |
| 39. Social work interventions | Furstenberg & Olson | 53 |
| 40. Staff education | Ryan | 23 |
| 41. St. Mary's Hospital (London) Program | Miller & Green | 28 |
| 42. St. Vincent's Medical Center (New York City) staff education program | *Hospitals* | 14 |
| 43. Walter Reed Army Medical Center Social Work program | Gemmill | 3 |
| | Gemmill & Kuzmick | 2 |
| | Piotroski | 4 |
| 44. Queens Hospital Center (New York City) program recommendations | Rosner, Shapiro & Howard | 70 |

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# Ministry with HIV-AIDS Patients

# A Professional and Personal Journey

**Karen T. Chrisley**

It was August, 1986, and after only three months on station, I was still exploring the huge maze of floors filled with patients, staff, support and administrative sections of Wilford Hall Air Force Medical Center, at Lackland AF Base in San Antonio, Texas, where daily I stumbled across a new area of hurt or of healing.

Some would say that it was God who led me to a particular ward on a particular day, others would say that it was merely a matter of chance when I discovered the new AIDS treatment unit. I prefer to think God led me, because before that discovery I did not know what an adventure there could be in hospital ministry!

As I left the elevator, I noticed something different about this floor. Perhaps it was the energy of the staff . . . whatever it was it beckoned and invited this curious chaplain. Upon reflection, it was not difficult to understand why I was drawn there. It was all so new—everything was new: the doctor, the nurse, the patients, policy and procedures, the manifestations of the disease, even the disease was new, so new that its terminology was still being developed; and the newest of the new was to be this chaplain. What started as curious inquiry into the work of a ward, became for me a passion for ministry, a ministry to those infected by the Human Immunodeficiency Virus.

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Chaplain, Major Karen T. Chrisley, USAF, serves the Directorate of Pastoral Care of Wilford Hall USAF Medical Center, Lackland Air Force Base, San Antonio, Texas. Chaplain Chrisley holds a Doctor of Ministry from the Pacific School of Religion. She was ordained an elder in the United Methodist Church in 1976 and began her chaplaincy in 1977. Her assignments include McChord AFB, Washington, to the RAF at Lakenheath, England, and Brooke Army Medical Center.

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The first Acquired Immunodeficiency Syndrome related case at WHMC was probably in 1979 when an airman basic donated infected blood which was given to a retiree. Of course, that was not understood until both died in the early 1980s when the laboratory staff did a "look back" procedure. Military communities reflect the sociological makeup of the United States and the ramifications of the HIV epidemic is no exception. The next case was noted in 1983, the same time that the country as a whole was beginning to hear of this new disease.

During this time one or two cases appeared a month, but as early as 1983 WHMC had been designated as the referral hospital for all Air Force personnel infected with HIV. In September 1986, the Department of Defense mandatory all forces testing for HIV was established, and the influx of patients as a result of this testing tied up a ward; and then, within a few weeks, two wards. The unit at that time had one doctor and one assistant, (working only with HIV patients), who found themselves swept into a new and often frustrating field of medicine.

Collecting data, research, training staff, recommending new policies, while each day learning more and more about their patients' symptoms, produced a peculiar sense of adventure for our newly formed staff and team. To be a part of this team was a privilege. The journey was to be one of suffering, mystery, discovery and grace; and a chance to practice wholistic medicine, which is so vital to the HIV patient. The HIV patients are affected in all areas of their lives when diagnosed, so working closely with the doctors, nursing staff, technicians and other health care givers, proves invaluable in assisting these patients to come to grips with what is happening to them. Since those modest and rapid beginnings, the program has increased to a staff of three full time doctors, nurses, and qualified technicians and support staff and, of course, Protestant and Roman Catholic chaplains.

As conditions and observations demanded, other improvements were made. Additional support such as more administrative assistance for doctors and patients, the relocation of the environmental health section on the same floor, and continuation of some of the nursing staff, has helped tremendously. An HIV Professional Working Committee meets once a month to allow for representatives of the diverse agencies within the medical center to discuss formally and informally policies and patient issues.

These changes and improvements were not made easily. At first, a dedicated, but often frustrated staff, struggled to be medically efficient for the incoming, displaced patients but were frequently stymied because of ever-changing situations. Lack of education about this disease, for example, led to some patients being treated inhumanely by their commanders, support personnel, legal counsels,

and even the medical system itself. For a few months, there didn't seem to be one patient who did not tell a horror story of the treatment he or she had received upon notification of being HIV-positive. Patients arrived angry, hostile and non-compliant to the wishes of the physicians and staff.

WHMC chaplains, and at least one USAFE chaplain, helped to bring these incidents to the awareness of those in power who could make changes. Changes were made. It is rare today that any HIV patient enters WHMC with such stories.

So excitement and newness did not mean an easy journey. When people are involved there are no easy answers. Any chaplain who has dealt with people in crisis can relate to the urgency of time. For the patients on this ward the time factor was an unknown. For staff and patients there were no books to read, workshops to attend, and for me no experienced pastors in the area to call on for help. All of us, the doctors, staff and chaplain, found ourselves on the frontier of this disease and its treatment.

There came a time when we began responsibly to design and to create our own styles for treating the patients. As a chaplain, my first resource was Holy Scripture, but read and studied within a new context.

The ancient story of the Good Samaritan (*Luke* 10:30-37) reaffirmed within me what my Christian tradition taught. The Samaritan never asked why the beaten man was abandoned in the ditch, or who he was, or what his social status was, or about his lifestyle. He was called to serve him; to minister to him. He did not even call judgment upon those who left him there to die. He simply did what was needed to be done. Capturing a vision from scripture such as this helps to dispell the cultural beggage that could quite easily impede ministry.

The words "journey," "excitement," "suffering," and "passion," have been used in this article. Those are the results of dealing with the questions that I had as I entered the world of HIV-AIDS patients.

Where does the Chaplain fit into this scheme of things on a ward such as this? In much the same way as some chaplains seem to be more effective on the cancer ward than ob-gyn, or deal better with family than basic trainees; so, too, are some better prepared for ministry with those who have been infected with the HIV virus. But do not cheat yourself of this suffering, rewarding ministry solely because of trepidation and initial fears.

This disease, AIDS, is an Air Force Family disease (over 650 active duty, spouses, children, babies and teens have been diagnosed). Every chaplain in uniform will be offered the opportunity to be within this ministry somewhere, sometime.

The chaplain must understand just who, and whose, this

person with HIV is and how the chaplain can minister with integrity. There are those who do not believe in divorce; but minister very effectively to the divorced. There ar those who do not approve of alcohol; but minister well to the alcoholic. There are those who are not married, but minister to the family compassionately. Shall not also we visit the sick and be present to them, sharing the love, acceptance, and peace modeled by our Lord Jesus Christ? After all, our Lord chose to be among the rejected, the socially unacceptable, and the alienated. If that was his "model for ministry," how can we who claim to follow Him choose another?

In this program, as with others in the hospital, there are three main areas of ministry: ministry to patients, ministry to the staff, and ministry as education. Every skill that a chaplain has is put to the test. Issues such as death and dying, denial of illness, low self esteem, alienation from God's love, hidden and overt anger, wrestling with questions such as "How do I face my family?" are raised daily in this ministry. These issues are not new to the field of medicine nor Clinical Pastoral Education, but they have a different twist when they are presented in the sharpest way by patients who often appear to be healthy.

## Patients

Soon after the numbers of HIV patients started climbing, it became apparent that there was a need for an intentional ministry. The patients, who perceived that they had been given a death sentence, were for the most part young. Most had not thought about a value systems, let alone choosing to change one. Some who had already experienced rejection, now felt as if all of society had turned against them. As one member of the hospital staff observed, "They are the outcasts of the outcast!"

To be classified as an AIDS patient equates with the loss of hope. As the patients become experts about their own illness, conversations center around symptoms and comparisons of the T-cell count (the designator of the Walter Reed classification) as if they were comparing scores of ball games—winners and losers! The tension and fear mounts on the floor when one of the patients is dying.

Above all, the chaplain must listen. There is much to hear. Anger and frustration vented—some against the disease and how it has cheated them, some toward former friends and family who have rejected them, some directed toward the churches and how they perceive AIDS patients.

When one patient's diagnosis became known, for example, his wife and two children left him, and his church told him he was not welcomed. When he came to WHMC, we are able to find a spiritual leader of his tradition who would minister to him. Now the patient is

dying. He is sad about many things, but rejoices in his ability to worship and to receive the love of God.

An atmosphere of frustration can permeate the unit. Frustration with those whose defenses are built so high that no one can reach them. Frustrations with those who are so close to death, and frustration because there is not enough time or energy. The health care provider can become a victim of burn out.

Are there only sad memories? Certainly not. For example, each year those active duty personnel who have been identified with the HIV virus return to WHMC for re-evaluation. A couple of months ago, one of the patients who became a Christian during his first WHMC visit, returned and asked me to baptize him. He explained, "I have waited until I returned because it was here that I met Christ and it is here that I wish to be baptized. I want you to do it!"

One young man who had planned to leave the Air Force to enter seminary, assumed that his church would no longer accept him. He learned that the officials would welcome him to the seminary, and that they would "somehow" work out "something." One man expected his wife to leave him as soon as he told her. After being informed of his illness, she arrived at WHMC on the next plane to offer him support.

Mothers and fathers, whom the patients thought would never understand, offered their homes to patients and even once to a son's friend infected with HIV. *Romans* 8:28 states that "all things can work for the good for those who love the Lord . . . " This particular scripture has been proven over the over again in the HIV program!

## Staff

A ministry of presence is the ministry to the staff. As with any group, there are those who wish to talk with the chaplain and those who do not. I test this out by walking through the 'H' shaped ward talking, making physical contact, seeking out the referrals made by the staff and stopping at one or both of the charge nurse's stations to visit. As on any other floor in the hospital, the attitude of the staff is vital to the healing process.

The members of the nursing and technical staff are often the same age as the dying patient. They are shocked that death is so close to one of their own age. AIDS brings fear, anxiety, and burnout to the staff.

Early on, before educational efforts were prevalent in the hospital, other staff members discriminated against these staff members because of their work with AIDS patients. This brought added stresses, socially and professionally, that most had never before experienced.

It is important for the staff to have some time, and someone with whom to brave dialogue. The staff, especially the younger staff, needs to talk about the dying patients, the stress of taking care of patients who are in denial, and to discuss their own prejudices and judgments. The chaplains' offer and guarantee of confidentiality is an asset not only for the patients but for the staff as well.

## Education

Often chaplains are the best people to stop rumors, and to dispell myths. Not being medically qualified as a doctor or nurse is no reason for the chaplain to remain ignorant of the facts about AIDS. I soon learned that I had a moral obligation to keep as current as possible. I visit several different sections of the hospital daily and during these visits there are often statements made or questions asked about HIV which are the results of misinformation.

Usually people want to know the facts, and offering books to read, doctors to talk with, or simply inviting them to the next workshop can dispell many fears. To share information has become for me an obvious extension of ministry.

Besides the in-house educational effort for the hospital staff, during the last 18 months there have been two workshops for military chaplains, one for civilian clergy, articles and talks given and visits to local churches to assist local pastors in educating their congregations.

Many of the medically retired HIV patients have chosen to locate in the San Antonio area. Responsible information with spiritual guidance shared with the civilian community eases the transition for former Air Force personnel. The sharing of ministry and information provides networking for staff and gives the opportunity to explore different styles of ministry.

I have been asked if this is a ministry of little hope and much discouragement. As I reflect upon this ministry, I come to the conclusion that there were not as many words of discouragement as words of encouragement. Were there words or actions of prejudice and discrimination? Not as many as of openness and willingness to share in this ministry.

Retaliation for risking? There is none which can measure up against the image of a young man regaining his dignity and looking forward to a new life (even if it is comparatively short) with his God.

A ministry involved with suffering? Yes, indeed. Whether it is holding a patient while he is going through a particularly painful procedure, or crying with him because he has to call his wife and tell her that he is HIV-positive—it is painful. Yes, there is always suffering in this ministry—but this is a ministry of HOPE. There has been medical progress since 1986 due to the dedicated research that has taken place throughout the world. Where once there were no options for the patients, there now are some. There is always hope

for a cure, and just knowing that there are researchers, even in the San Antonio area, working unselfishly on a cure for this disease gives the patients hope. There is another kind of hope that we who are chaplains represent. We bring a spiritual hope to empty, frightened lives. When patients begin to experience a God who loves them unconditionally, hope takes root within their souls. The concern for eternal life is always present to these patients. For some, it has become the answer for life. Some are quite articulate about their newly discovered spiritual future, but most keep the promises of God close to their hearts. It may be for some the first time in their lives that there has been a stability, a peace, within their souls.

Thanks to God, I have been blessed to be part of the sacred journey that staff and patients have taken throughout these months. The challenge I wish to offer to other clergy is not to miss the opportunity to share the Gospel, as our Lord did, to those on the edge of society. Today, the AIDS patient is at the edge, and there is no other journey in ministry like the journey of the AIDS ministry!

# Ministry To People With HIV

# Opportunity For Spiritual Awakening

**William R. Wood**

A very bright and articulate twelve year old boy sits across from me. We talk about card games and tell each other fishing stories. His fishing stories are clearly better than mine, and they elicit a good laugh from a corpsman drawing blood from the boy's arm. As I sit and talk to him, my mind wanders momentarily, and I think of my own twelve year old son. As we talk, I notice the eyes of his father and see in them his uneasiness. I sense his pain. His son has a retroactive virus, human immunodeficiency virus, HIV.

## A Parent's Pain

It is as if I hear the father crying: "This is not fair! Why my son? Will he develop AIDS? This can't be happening! God, where are you?" These questions that come from the pain of knowing that the virus has no cure elicit no easy answers for this father or for any of us who search anxiously for them.

This experience parallels the emotional and spiritual pain of many individuals confronted with the news that they are HIV-positive. This is a daily occurrence at the Portsmouth Naval Hospital where I work. Ministry to these people is both challenging and exhausting. It is painful and sad, and sometimes it is joyful and humorous. The Portsmouth Naval Hospital is one of four Naval

[1] Institute of Medicine National Academy of Sciences, *Confronting AIDS: Directions for Public Health, Health Care*, and *Research*, (National Academy Press, Washington, D.C. 1986) p. 5-6.

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Lieutenant William R. Hood, CHC, USNR, serves as chaplain to the Portsmouth Naval Hospital, Portsmouth, Virginia. Chaplain Hood's ministry in the armed forces is endorsed by the Episcopal Church.

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Hospitals designated for HIV evaluation, study, and follow up. The Pastoral Care Staff is an integral part of the treatment team helping the individuals who are confronted with the harsh realities of this diagnosis.

## Implications For Ministry

### Epidemic Proportions

HIV is a virus affecting the immune system and causes the destruction of certain critical white blood cells named T-lymphocytes. The origin of the virus is not clear, but it has reached epidemic proportions throughout the human population. To be diagnosed as seropositive, as having the virus, does not necessarily mean that the person infected will develop AIDS. This fact illustrated how essential it is for fantasy to be separated from reality in matters concerning this disease. There are many stages within the growth pattern and development of the virus before AIDS develops. A person who is asymptomatic is classified as having the HIV virus, but no related illness. Persons who are asymptomatic comprise the largest population of individuals coming to the hospital for evaluation. They are individuals who are healthy, except for the presence of the virus, and have no symptoms related to AIDS or the AIDS related complex (ARC).

With the Navy's program for required HIV screening, individuals carrying the virus are being identified and evaluated. From the statistics complied at the Portsmouth Naval Hospital thus far, people who come in for evaluation can be generally described as follows:

* Ages 22-24.
* On their second enlistment.
* Of Petty Officer rank.
* Excellent Navy records.

They are not unusual people who can be singled out. They are, however, individuals who have acquired a devastating disease.

## HIV Education Essential

Chaplains and other care givers must become as educated as possible on the subject of HIV. Knowledge eliminates fears about the virus, and many of the anxieties felt by patients, staff, and other significant people can be lessened through education. Only through proper understanding of the physical, emotional, and spiritual dynamics of this illness can viable ministry proceed. Without education, fear drives our dealing with this crisis.

HIV strikes men, women, and children. It knows no racial or sexual boundaries. It affects all sorts and conditions of humanity. The fear of being exposed to the virus is real, but current scientific

research denies the possibility of transmission through casual contact. It is not contracted in the exercise of pastoral ministry.

## Convenanting Relationships

Alastair Campbell, writing in his book *Professional Care*, makes a very important point about ministry to those who suffer.[2] Campbell's point, not a new one, is that we chaplains should express our relationship with those we minister to in terms of covenant. This is a most important concept when dealing with an HIV patient. There is a temptation to provide easy answers or to point blame at a group of people. We need to be reminded that the Jewish and Christian God is a God of forgiveness who is constantly calling people back. What a tragedy if we who are God's representatives should estrange those who need to hear this message of hope, forgiveness, and support. Keeping covenant with God's people means taking people where they are and pointing the way to hope.

People who come into the hospital for HIV evaluation are in a position to begin to hear the hope and care of God through a vital and proactive ministry. Most of these individuals are in reasonably good health when they arrive for their first evaluation. They are suffering, however, from a multitude of problems—spiritual and emotional. Significant pastoral care and spiritual intervention can take place at this time.

## Patient Ministry

### Notification Problems

When an individual is identified as infected with the virus through random command screening or predeployment testing, notification is sent to the commanding officer alerting him of the need for further testing and evaluation. Someone in the commend then informs the individual that they carry the virus. Informing the individual is traumatizing and often handled badly. Because some remain uneducated about HIV, they act out their fears on others. In one instance, an individual was informed on the 1MC. Imagine the stress, the fear, and the pain that caused. In many instances, stories have been shared with me in which the person is told they have AIDS and will die soon, or that the person is very, very sick, although asymptomatic. Many are packed up and shipped out in a matter of minutes.

[2] Alastair V. Campbell, *Caring and Being Cared For*, on Moral Medicine: Theological Perspective in Medical Ethics, Edited by Stephen Lammers and Allen Verhey, (William B. Eerdmans Publishing Company, Grand Rapids, Michigan 1987), p. 267.

Individuals coming to the hospital are usually in a state of shock, and this causes a variety of pastoral challenges. At the least, the chaplain must let the person know that someone really cares for them and understands their situation. In this phase of ministry, it is important to simply let the person know that a chaplain is present and caring. This initial meeting may not be remembered, or may be met with a numbed silence, yet it is most important that the contact be established as soon as possible.

Shock is coupled with fear, and the person who has just been told they are HIV-positive faces a variety of different fears:

* Fear of what being HIV positive means.
* Fear of the hospital.
* Fear of what others will think.
* Fear of being alone to face this crisis.

With diagnosis and notification, the individual is suddenly thrust into a frightening situation. He or she hears life-shattering news alone, far from primary support groups of friends, family and familiar surroundings. One of the important tasks for the staff is to greet these individuals, to reassure them that they are not alone, and to show genuine concern. Reassuring the HIV positive patient that they are in a safe and caring environment helps ease some of the pressure created by having been informed of the illness.

The person is next involved in a 7-10 day evaluation and education process. During the stay in the hospital opportunities exist for pastoral support and for working through some of the life issues the person faces. The patients meet in a support group three times a week to discuss a variety of issues which they hold in common. By sitting in on this group, chaplains can help to uncover specific pastoral and theological issues and encourage further discussion of them. "How can a loving God allow a virus like HIV to exist?" "Am I still loved by God?" "Does God even care?" "Will God be with me and support me?" These questions may well be the beginning of a journey to find God and to be found by God.

## Accepting the Reality

As these men and women begin to deal with their shock and fear, many begin to accept the reality of the disease. At this point, the patient may try to escape the situation through denial. On the surface, many appear to be in control and unconcerned about what is happening. Further dialogue reveals, however, that they are trying to avoid the truth that their lives are forever changed. This denial can manifest itself in a variety of ways. Sometimes patients express a lack

of concern about lifestyle changes that must be made. Sometimes it is in their unwillingness to become more educated. Many can scarcely believe what has happened and do not recognize their need for help in dealing with such an overwhelming crisis.

## Season of Anger

During this time the person may challenge the reality of their situation and lash out in anger. This is where the idea of covenant is helpful because it meets people where they are. Often, the anger is harsh, but in most cases it is not directed toward a specific person. By allowing the patient to vent frustration and to raise questions, the patient can be led to face and to deal with this new set of life and death issues. As the individual sees that care is given, regardless of emotional state, he or she becomes more receptive to the ministry provided.

Given the relatively short stay at the hospital, the ministry which can be done is limited. However, a time of reflection can begin. Many of these individuals are in the 18-35 age group, and they are questioning the values of spirituality. It is at this time, as Morton Kelsey [3] writes in his book, *The Other Side of Silence*, that a person's emotional and spiritual shell is cracked open. For many, this is the first time they admit the reality of their frail humanity so in need of the love and care of neighbor and of God.

## Sharing the Basic Tools

The basic tools of the spiritual life can be provided at this time to remind them of the value of prayer and the health and hope of their own religious tradition. At Portsmouth we work with individuals to help them form a concept of God which will enable them to move forward in their spiritual journey.

If they already have a religious grounding, it is important to direct them to their own tradition and to put them in touch again with their spirituality. By meeting people where they are and, as Bob Bennett [4] sings in one of his songs, "not shoot anyone with a high powered doctrine gun," chaplains can enable people to begin to address life and death issues and to discover that God is with them in the process.

## Approaching Family

Family issues are among the first to surface when the patient begins

[3] Morton T. Kelsey, *The Other Side of Silence: A Guide to Christian Meditation*, (Paulist Press, New York, Paramus, N.J. Toronto 1976), p. 42.

[4] Bob Bennett, "Madness Dancing", Matters of the Heart, (Priority Records, 1982).

to work past the feelings of shock and fear. One of the important questions discussed is how one might approach family members. Because there is still great misinformation about HIV, many patients are apprehensive about telling their families. This reluctance reinforces the feelings of loneliness. Questions about how to tell one's family are centered around acceptance and fear of rejection. For some individuals, it is easy to inform family members; for others, only time and further pastoral support will bring this about.

Hopefully, as these individuals leave the hospital and go back to their commands, they will find support, care and acceptance from other chaplains, spiritual leaders, and friends to meet their special spiritual needs. Because persons who are HIV-positive are protected by the Privacy Act, the chaplains at the individual's command will not be informed. Nevertheless, it is crucial for chaplains to become as educated on the matter of HIV as possible so that when approached by someone with HIV the chaplain can assist the individual to deal with the issues raised by this disease.

## The Future Journey

The diagnosis of HIV causes people to re-evaluate their lives in an honest way, because it underscores the mortality which most otherwise ignore or deny. Past, present, and future—on a very individual basis—are all confronted and sorted out in the midst of a raging storm of shock, fear, loneliness, and anger. In the seven to ten days these persons spend at the hospital some basic tools can be given to equip them for the work ahead. However, what is important for their continuing spiritual journey is the knowledge that members of the chaplain corps seek to meet their needs and are reaching out to minister and to care for them.

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# Support Group For HIV Patients

# One Form Of Pastoral Care

**Francisco J. Beltran**

> *Now there were four men who were lepers at the entrance to the gate; and they said to one another, "Why do we sit here till we die? If we say, let us enter the city, the famine is in the city, and we shall die there; and if we sit here, we die also. So now come, let us go over to the camp of the Syrians; if they spare our lives we shall live, and if they kill us we shall but die."*
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> II Kings 7:3-4

In this short biblical account, so quickly read, it is easy to feel the helplessness and hopelessness of these four men with leprosy. It seemed to them that regardless of where they turned, or whatever they planned, they would surely die.

The present epidemic and medical crisis known as AIDS presents a modern parallel to this Bible story. Society, today as in biblical times, reacts with fear and with the rejection of the victims of this dreadful disease. This reponse is made, of course, depite the profound emotional, psychological, and spiritual needs of those who suffer.

In January of 1986, Walter Reed Army Medical Center, Washington, D.C., began to admit HIV-positive patients. At that time Chaplain John Goodman, an Air Force chaplain studying

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Chaplain (Major) Francisco Beltran, a United Church of Christ pastor, is presently serving as senior floor chaplain at Walter Reed Army Medical Center, Washington, D.C. Chaplain Beltran holds degrees from the Divinity School, Silliman University, in the Philippines and G. Peabody College of Vanderbilt University, Nashville, Tennessee. He is a graduate of Clinical Pastoral Education (4 Quarters) at Walter Reed Army Medical Center, and his previous assignments include the 75th Field Artillery Group, Fort Sill, Oklahoma and 3d Bde, 8th Infantry Division (MECH) in West Germany.

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Clinical Pastoral Education, and I began an unstructured support group for some fifteen AIDS patients. From a modest beginning, the group soon grew into a more sophisticated and structured group led by another chaplain and Mr. Stan Piotroski, the social worker assigned to these patients. After a time, these two professionals became the leading facilitators for the support group.

Facilitators have important roles to play in such support groups. There is a great need to play the role of one who understands human nature and shows deep empathy to the plight of those who are experiencing rejection, loss and even death. W. R. Bion, an authority in group work stresses that "the group is met in order to be sustained by a leader on whom it depends for nourishment, material and spiritual, and protection." [1] This reinforces the need of the group leader/ facilitator to be aware that group members come to be "fed", to receive "treatment," acceptance, care and even love.

## Format Of The Group Process

The support group met twice a week, on Tuesday and Thursday mornings from 0930-1100 hours. Attendance was mandatory for HIV-positive patients, and especially required for those patients newly admitted for the staging process. The group met in a large lounge, but in a space restructured to provide privacy for the group. For the meetings of the group, some twelve to twenty people would sit in a circle, chairs touching side by side, to create a sense of oneness and security. At the beginning of each session, as an opening statement, one facilitator would define the purpose of the gathering: to maintain health, to encourage hope, to permit the free expressions of feelings and ideas.

Going from one person to another in the circle, participants were asked for three pieces of information:

a. Name, or what they wanted to be called.
b. The date of their diagnosis. (Follows AA approach for sensitizing individuals, and facilitates acceptance themselves and others.
c. Group rules (The group owns the meeting and each participant has the opportunity to govern it by giving a rule to be observed.

The following are examples of the rules that the group members developed in order to have order in the meeting.

1. No smoking.
2. No eating. Drinking coffee, tea or soda were allowed.
3. Confidentiality. (Except in matters of life and death.) The facilitators, however, had the right to discuss particular issues with the patient's medical doctor. (Confidential information disclosed to

the facilitator during a personal counseling session was to remain confidential).

4. Participants were free to discuss anything they felt comfortable with.

5. One speaker at a time.

6. Respect the opinions and feelings of one another.

7. No violence.

8. To start on time and to end on time.

9. No one was to leave the room, unless for a doctor's appointment, or for a personal emergency need.

Aside from these self-imposed rules developed by the group of participants, the sessions were generally governed by the conventional three "Ps" of support groups:

a. Privacy

b. Protection

c. Permission

These three factors are self-explanatory and serve to promote trust, confidence, spontaneity of expression, honesty, self-disclosure and the non-judgmental acceptance by others.

## Issues Raised

Eight issues can be defined as the most common and pressing concerns raised by the group participants in the context of the support group meetings.

1. Anger. Anger toward the person who may have transmitted the virus. Anger directed toward the medical profession which could not "cure" them. Anger directed toward God, and anger directed toward themselves.

2. Fear of death. Perhaps for the first time in their lives, these young adults—18 to 30 years olds—were becoming aware of their mortality. They asked such questions as: If we are dying, how will we die? Painfully, disfigured, alone?

3. How to break the news. (With whom do we want to share this information—parents, brothers, sisters, spouse, grandparents, friends, lovers? Will we be accepted after sharing this news?) During the many sessions, participants expressed different levels of acceptance and rejection by their loved ones. A number received total acceptance from family members. Once a convoy of cars filled with parents, uncles, aunts, grandparents, nephews and nieces arrived from a midwest city to visit a patient. The other extreme is illustrated by a young soldier who was totally rejected by his own parents and brothers, to be accepted only by his sister. Participants agreed not to tell the diagnosis to their significant others by telephone. Many

waited until they had the opportunity to go home. In addition to these personal methods of disclosure, medical doctors and nurses on the ward were willing to inform family members if the patient wished it.

4. Spiritual issues. The chaplain, as a group facilitator, needs to face the religious issues and must acquire a non-judgmental attitude, an open mind and empathy for these patients. As claimed by David Miller, a senior clinical psychologist and lecturer in psychiatry in London, "Biblical authority is often invoked in the blaming process, particularly where homosexuality is being discussed. Because homosexuality is described as sinful in parts of the Bible, the advent of AIDS is held up as proof of 'God's wrath' and as a vindication of anti-homosexual feelings." [2] On a number of occasions, group participants raised these profound and honest questions: "Is God punishing me?" "Why does God allow this dreadful thing to happen to me?" "Why me?" Throwing these questions before the whole group, individuals are not so much seeking definite answers as they are wanting to be assured that God and the people around them still care for their welfare. As for my own work, these deep and penetrating questions about life lead me into a more detailed person to person counseling and pastoral care in smaller groups or individually. These religious issues provided a clearer insight into the spiritual needs of the persons with AIDS. When these spiritual issues surfaced, I carefully made a follow-up visit to the patient's room. In the privacy of the individual's room or in my office, the patients were better able to pour out their feelings and to express their need to be close to God and to accept themselves. Prayers, scripture reading, communion, and special services were often important parts of this self-acceptance and spiritual healing.

5. Need for Comfort and Friendship. The sad feelings these patients are experiencing come from the fact that society has rejected them. Among themselves, these patients become friends. Through this support group, individuals find out they are not alone; there are also others who suffer with them and who understand them as well.

6. "Guinea Pig." This issue seemed to evenly divide the patients when they talked of submitting themselves as "guinea pigs." Few patients were directly involved and few signed a protocol voluntarily submitting themselves to experimental drugs for a certain period of time. In the spirit of altruism, however, at least three patients shared their experiences with the group—their deep fears, their high hopes, their willingness to take risk. One patient declared, "What's there to lose? There's much to gain for me and for others." Despite possible adverse side effects of the new medications, these patients felt good about what they are trying to do for themselves and for others who might profit from the experiments.

7. Safer Sex. A number of patients expressed some lack of sexual desire, and in particular, a disinterest in the manner of sexual contact by which they acquired the illness. But many of the young adults indicated a growing interest in sex. They know no one could prevent them from relating sexually with other persons. A number of the patients expressed some sense of responsibility for themselves and for their future partners. Some shared their plans of getting married. They openly discussed ways of expressing sexual desire in safer ways, and discussed the moral and legal implications of their sexual contacts.

8. Pregnant Patients. The growing number of female patients with AIDS being admitted at Walter Reed Army Medical Center constitute a very special part of the AIDS patient population. They are either active duty military personnel or family members. A few of them are in the early stage of pregnancy. Fear and anxiety for these patients are increased because there is a 50% to 80% chance that they will give birth to babies who are infected with the virus. Most of these patients request some personal, religious, and psychiatric counseling.

# The Pastoral Care of AIDS Patients

**Max P. Metcalf**

AIDS has been diagnosed in 36,000 people in the United States.[1] This epidemic is expected to grow to 250,000 cases by 1991.[2] A Public Health Service conference estimates that up to 1.5 million citizens in the United States are infected with the virus.[3] (See Illustration I)

This growing epidemic has created a corresponding need for chaplains to learn to give pastoral care to AIDS patients. This article was first given as a paper at the Sixth Army Chaplain School held in Costa Mesa, California, in January 1988. My resources include experience in direct bedside patient pastoral care for AIDS patients and their families in the 700 bed Veterans Administration Medical Center in Portland, Oregon; membership on the Medical Center's AIDS TASK FORCE; and the AIDS Patient Support Committee. I regularly conduct teaching rounds for student chaplains from two seminaries which often include visits with AIDS patients.

## Medicine, Law and Theology

With law and medicine, it is my belief that theology has an important role to play in the support of those who care for AIDS patients.

[1] Donald Hopkins, M.D., Public Health Reports. Vol. 2, No. 5, October 1987, pg. 466.

[2] Francis and Chin, M.D.s "Prevention of AIDS in the U.S.A.", Journal of American Medical Association. March, 1987, pg. 1357.

[3] Hopkins, Op. Cit.

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Although doctors and lawyers agree on most issues dealing with the AIDS epidemic, there are some issues where there is lively debate. The main debate, for example, concerns the opposite positions taken by those who advocate massive testing and accurate patient histories at the expense of privacy and confidentiality, and those for whom the protection of privacy and confidentiality is of primary value. Theology, in my opinion, can usefully speak to those engaged in this debate.

The chart below illustrates the number of AIDS cases reported in the twelve western states covering the U.S. Sixth Army area as of December 1987:

| STATE | POPULATION * (per thousand) | NO. of CASES ** | % OF U.S. Cases |
|---|---|---|---|
| Alaska | 4,409 | 36 | 0.1 |
| Arizona | 3,187 | 375 | 0.8 |
| California | 26,365 | 10954 | 22.0 |
| Colorado | 3,321 | 521 | 1.0 |
| Hawaii | 1,054 | 182 | 0.4 |
| Idaho | 1,005 | 16 | 0.0 |
| Montana | 826 | 13 | 0.0 |
| New Mexico | 1,450 | 90 | 0.2 |
| Nevada | 936 | 152 | 0.3 |
| Oregon | 2,687 | 279 | 0.6 |
| Utah | 1,645 | 90 | 0.2 |
| Washington | 4,409 | 675 | 1.4 |
| Wyoming | 509 | 8 | 0.0 |

Illustration I

* Population based on adjusted 1985 estimates.
** Based on AIDS Weekly Surveillance Report CDC, December 28, 1987, Oregon Health Division Report, Volume 37, No. 3, Feb. 1988.

## The Dilemma Of Medicine

In the October, 1987, issue of the Journal of Hospital Ethics, a case is reported where three medical staff members were exposed to the blood of an HIV-positive patient in a Milwaukee hospital. All three became contaminated by this accident and became HIV positive. This caused a local surgeon to refuse to operate on HIV positive patients.[4]

The Hastings Center Report of February, 1987, reports another type of dilemma. It presents the ethical problem a physician

[4] "Rights VS. Duties in Care of AIDS Patients-Collision Course", Journal of Hospital Ethics. October 1987, pg. 11.

faced with a patient who just tested HIV-positive. The patient was engaged to be married. His doctor counseled the patient to inform his future wife. The patient refused, stating it would ruin his marriage plans and create family troubles. If the doctor decides to inform the woman of the life threatening potential contamination from the patient, the patient can sue the doctor for breaking confidentiality. If the doctor does not inform her, when she becomes positive, she can sue the doctor for not observing public health standards.[5]

Such moral, ethical and legal dilemmas as these have created the need for new professional ethical guidance in the diagnosis and treatment of AIDS for medical professionals.[6]

## The Dilemma Of Law

While a primary concern of the medical community is contamination, the legal profession appears to be moving towards more protection of patient's privacy and confidentiality. They fear, for example, for the loss of their client's insurance and job because of discrimination against AIDS patients. The Harvard Seminars on "AIDS And The Law" offers important guidance to those of the legal profession. It suggests four areas of legal responsibility when dealing with AIDS:

> Public policy should be developed by state and federal legislatures.
>
> Public funding, both state and federal, should be increased to support public health, research and treatment.
>
> Legislative steps should be taken to provide massive testing and quarantine.
>
> Protective legislation should be passed to prevent discrimination.[7]

Writers in the arena of pastoral care for AIDS patients take up the cause for protecting the confidentiality and privacy of individuals and the information regarding their disease.

> In the context of HIV infection or AIDS-related diagnoses, rules of informed consent require minimally that individuals be informed if tested for antibodies to the AIDS virus and that their status or AIDS

[5] "Hastings Center Report", February 1987, pg. 22.

[6] Zugar and Miles, M.D.s "Physicians, AIDS and Occupational Risks", Journal of American Medical Association. October 1987, pg. 1924.

[7] Harvard Seminars, "AIDS And The Law", Law, Medicine, and Health Care. Summer, 1987.

related diagnosis may not be disclosed without their permission.[8]

Yet, the same authors understand the principle of greater good in protecting others from the virus by expressing concern that sex partners of AIDS infected people be informed of the danger. However, they support the mandatory screening of prostitutes for HIV infection, but not for homosexuals.[9] In fact, they seem to condone the gay male lifestyle, by offering guidance on how pastoral counselors may assist a homosexual's male lover to gain legal power of attorney.

> A homosexual male may have a lover who is in the same relationship as a spouse in a heterosexual marriage. In this situation, it is therefore advisable for a patient to execute durable power of attorney identifying and empowering the chosen person to act in his behalf when he is unable to do so. This process can assure that a lover is recognized to have the appropriate authority to make decisions, should a person become incompetent.[10]

## Ethical Vapor Lock

While there may be some debate between the professions of medicine and law, it is my observation that the theological profession is suffering from a severe case of ethical vapor lock. On one hand fundamentalist preachers condemn AIDS victims as receiving God's justice and punishment. On the other hand liberal activists promote gay rights and thereby suggest homosexuality to be an ethically acceptable lifestyle. Both religious camps use buzz word brainwashing labels such as "sick perverts" and "homophobics." Both camps have developed their own "psyop" terms, inventing polysyllabic word salads which belong to "Trash Can" theology. The AIDS patient should neither be judged nor condemned.

## Help Prevent Discrimination

The military and Veterans Administration chaplains have the responsibility to help prevent discriminatory actions and comments by other professionals, whether lawyers, doctors or clergy, by soldiers or other patients. The V.A. has an excellent policy regarding AIDS confidentiality. A national V.A. satellite TV AIDS Seminar explained the V.A. policy: to prevent discrimination against AIDS patients by keeping

[8] Ronald Sunderland and Earl Shelp, "AIDS. A Manual For Pastoral Care." (Westminster Press, 1987), pg. 46.

[9] Ibid., 47.

[10] Ibid.

AIDS information from getting into unsympathetic hands.[11] The key phrase, "who can help the patient" give access to needed information and research data.

I believe, however, the chaplain has an even greater responsibility to the AIDS patient. The chaplain should give both pastoral care and ethical counseling. The chaplain is most likely to be approached for help by the AIDS patient when that person first discovers that he or she is HIV-positive. There are several steps to developing good rapport with the AIDS patient.

First, set the right tone on the first visit. Since you can't hatch eggs in an icebox, don't be aloof and cool towards the AIDS patient. Build rapport through acceptance of the patient, even though you might not approve of the patient's lifestyle.

Second, do not be judgmental or critical. Avoid demeaning or paternalistic attitudes.

Third, be observant about any personal touches the patient may have around the bedside or room. Pictures, books, Bibles, prayer books, clothes, or other personal articles provide openings for conversation.

Fourth, when you ask questions about the personal or medical history of the patient, avoid rigid or structured questions which can give the impression that you are being mechanical and disinterested.

## Ethical Counseling

Pastoral care does not occur in an ethical vacuum. The V.A. and military chaplains are able to give ethical counseling because it is a part of our prophetic ministry. It is critical to have first established good pastoral rapport. If this is not done, the patient may feel the chaplain is preaching at him instead of guiding him toward ethical responsibility.

AIDS patients expect and deserve the best medical care the society can give them. But the AIDS patient has an ethical responsibility to society as well. Based on this understanding, I have defined several areas of ethical responsibility which I believe chaplains should address with their AIDS patients.

## Accurate History

The AIDS epidemic cannot be stopped unless medical researchers have accurate information from persons who are HIV-positive and from AIDS patients. The chaplain needs to counsel the patient on his or her ethical responsibility to give accurate and full disclosure of their medical, social and sexual history. Accurate medical histories,

[11] AIDS Education Seminar Telecast, received Portland VAMC, February 16, 1988.

for example, are needed for epidemiology research and treatment research.

## Quit High Risk Activities

Once a person knows that he or she carries the deadly virus, an ethical responsibility to society and to other persons demands they quit high risk activities which spread the epidemic. Chaplains should reinforce this responsibility and be ready to refer the persons who are HIV-positive to other medical professionals for help in quitting. This may involve counseling for drug abuse as well as gay lifestyle and heterosexual contacts.

> Absolute safe sex is that within mutually monogamous relationships in which neither person carries the virus. Although this has been an era of easy, irresponsible oversex, it is now a great time to practice sexual monogamy.[12]

## Refrain From Donor Activities

HIV positive victims should be immediately counseled to stop blood donations, sperm bank donations, and organ transplants. They should be counseled about changing any organ donor cards they may carry.

## Release of Partners' Names

All names of all sexual partners of HIV-positive and AIDS patients should be freely given to health professionals. Ethical responsibility dictates that accurate information is essential on this subject to control and eventually to stop the AIDS epidemic.

## Isolation Agreement

Hospitalized AIDS patients should be willing to be placed in isolation, if requested by the medical staff. This is a hotly debated subject among hospital staffs and a frequent topic at the meetings of hospital ethics committees. The V.A. position is that standard universal precautions are observed, rather than isolation.[13] The

[12] Bruce Dan, M.D., "The Years Of Living Dangerously", Journal of American Medical Association. March 1987, p. 1376.

[13] AIDS Telecast, Op. Cit. American Medical Association. (March 1987), 1357.

News Section: "Rights Vs. Duties in Care of AIDS Patients-Collision Course" Hospital Ethics. October 1987.

Hastings Center Report. October 1987 Hastings-on Hudson, N.Y.

Zugar, Abigail and Miles, Steven "Physicians, AIDS, and Occupational Risk" Journal of American Medical Association. (October, 1987), 1924.

motive for isolation is to protect the entire medical staff and visitors. The motive against isolation is to protect the patient from having the AIDS label. The chaplain's role here is to explain the policy which is chosen and help patients, staff and visitors observe it.

Most of these ethical responsibilities will be addressed in the earliest pastoral care of the AIDS patient when he or she first learns of being HIV-positive. Since HIV positive patients are treated at first as outpatients, I recommend chaplains be given regular referrals of AIDS patients from outpatient clinic staffs. Ethical counseling from a chaplain at this stage can help in obtaining accurate histories and can thereby contribute toward the control of the AIDS epidemic.

## Pastoral Care During Hospitalization

When the HIV-positive person becomes hospitalized with AIDS, the chaplain moves from ethical counseling into direct pastoral care. This involves diagnosing the patients pastoral care needs and then working up a pastoral care plan.

## Diagnosis Of The Patient's Pastoral Care Needs

Begin to develop a religious history of the patient taking note of relationships with parents, siblings, spouse, children and other people who influence the patient's life. Pay particular attention to those persons who are supportive and those who may be hostile or reject the patient. Make inquiries about relationships with other clergy.

Rank order the patient's pastoral care needs. Is the patient dealing with anger, rejection, depression, isolation, pain or the fear of death? You may find it helpful to use either the well known stages of grief by Kuebler-Ross or the hierarchy of needs by Maslow in the making or your pastoral diagnosis.

## Developing A Pastoral Care Plan

After your diagnosis of the patients pastoral care needs is finished, establish your pastoral care plan. In the beginning, the patient will welcome support from other individuals and groups. Later the support will often narrow to a one-to-one relationship of direct pastoral care by the chaplain alone.

Bringing in family, relatives, and friends for resolving interpersonal problems can help the AIDS patient deal with grief and

Harvard Seminars, "AIDS And The Law," Law, Medicine, and Health Care. (Summer, 1987).

Sunderland, Ronald and Shelp, Earl. "AIDS A Manual For Pastoral Care." Philadelphia: Westminster Press, 1987.

V.A. Satellite Network. "AIDS Education Seminar" Washington, D.C.: V.A. Central Office. 1988.

Dan Bruce. "The Years of Living Dangerously", Journal of American Medical Association. (March 1987).

despair. We frequently find that the former lifestyles of AIDS patients have caused reactions by family and friends. The chaplain can help heal these wounded relationships through group counseling. In some cases, a small family communion service or family devotions in the chapel or at bedside can seal restored relationships within families.

Eventually, the chaplain needs to address the AIDS patient's fear of death. In this context the chaplain provides scripture and sacraments in the tradition of the patient. Based on earlier pastoral diagnosis, the chaplain should be ready to provide the scriptures, the sacraments, and the rituals that are familiar to the patient. During the deterioration in the final stages of AIDS, patients may be shifted by the chaplain from counseling about relationships with people to counseling about a relationship with God.

In many denominations, this means the chaplain will want to meet the patient's pastoral care needs through hearing private confession of sins, guiding repentance, granting absolution, and assuring the patient of atonement with God.

When the chaplain has given ethical counseling along with direct pastoral care, then AIDS patients will find they will be accepted by the medical staff, their friends, and their family; just as they are already accepted by the Lord God in whose image they are created.

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# The Care of HTLV-III/AIDS Patients In The Navy

**Thomas E. Diamond**

HTLV-III stands for "human T-lymphotropic virus type III," the virus that causes Acquired Immune Deficiency Syndrome (AIDS). HTLV-III attacks and destroys certain white blood cells which are the body's first line of defense against invading germs. It may take several months to six years for the virus to cause AIDS. Present research indicates most people exposed to HTLV-III will develop AIDS.

## Contracting HTLV-III

HTLV-III/AIDS is spread through the exchange of body fluids, e.g., blood and semen. Those at high risk of contracting HTLV-III/AIDS are intravenous drug users who share needles; people who have anal, oral, or vaginal intercourse with a person who is infected with HTLV-III/AIDS; recipients of blood transfusions from a donor with HTLV-III/AIDS (Rare now because all donated blood is tested for HTLV-III antibodies); and babies whose mothers give them the disease during the pregnancy or at birth. Even though the AIDS virus has been found in saliva and tears, there is no evidence that the disease is spread through these body fluids. Casual contact with an HTLV-III/AIDS patient cannot transmit the disease.

## Testing for HTLV-III

To determine who has been infected by the virus, a blood sample is

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tested with a method which detects the presence of HTLV-III antibodies called "ELISA." The human body creates antibodies to kill germs that invade it, but HTLV-III antibodies do not kill the HTLV-III virus. A positive test for the antibodies indicates the person has been exposed to the HTLV-III virus. The last stage of the viral infection is AIDS. If the test is negative, the individual is considered a non-carrier. If the test is positive, the same sample is retested. If two of three results are negative, the individual is considered antibody free and no further testing is done. If two of three results are positive, the same blood sample is then sent to Bethesda for a test called "Western Blot." A positive result confirms the presence of the HTLV-III antibody and the individual is sent to a naval hospital at Portsmouth, Bethesda, San Diego, or Oakland for medical evaluation to determine if the immune system is fully functional. This evaluation takes from one to two weeks. During this time, the ELISA and Western Blot tests are repeated to ensure the initial test results were accurate.

At the end of the evaluation, a determination is made as to the health of the individual and his or her fitness to remain on active duty. Those not showing signs of progressive illness or immune deficiencies are retained on active duty.

Individuals assigned to a ship will be transferred to a CONUS shore facility within a 300-mile radius of one of the naval hospitals mentioned above. This assignment is a precautionary matter for the individual. This tour will be for approximately one year. Those showing signs of progressive illness or signs of AIDS will be referred to a medical board for evaluation. Active duty members who are administratively discharged are eligible for treatment in the Veterans Administration system. Members found to be homosexual or intravenous drug users outside of medical consultation may be subject to administrative discharge without benefits in conjunction with SECNAVINST 5300.30. This will occur only if the patient denies homosexuality or intravenous drug use, yet has been positively found to fit one of these categories.

## Initial Visit

HTLV-III/AIDS has elicited a response of fear from the society and a societal stigma is placed on those who have contracted the disease. Therefore patients may be hesitant to talk at first about the problem, or may even indicate they do not wish to speak at all. To minister effectively, I let them know that I understand their fears, and that I am with them to help and not to downgrade or humiliate them. It may take two or three visits before patients will begin to discuss their problems and fears. As a chaplain, I must be willing to listen and assist and minister to them as I would to any other patient. I say this because one must confront this virus/disease on a personal basis first.

When I first started dealing with HTLV-III/AIDS patients, I felt very uncomfortable. I was afraid they might infect me with the disease. I prayed to God for personal strength to minister to these people and to offer them all the support I could. In the weeks that followed I found my fear subsiding, and found myself treating these patients as I did any other patient. I reached this point through prayer, through speaking with staff who provided daily care for the patients, and through seeing the strong support that many of the patients were receiving from their families. I also came to realize that these people needed spiritual support as others did. I have found my ministry to these patients to be very rewarding. Ministry can also be very frustrating when these patients refuse to open up, and I can see as a result that fear and frustration are destroying them.

## Express Feelings

The most common feelings that patients with HTLV-III have expressed range from fear of rejection, anxiety about the loss of a job and income, and the fear of death. The most common fear is the fear of being rejected by family and loved ones. One individual who was bisexual and engaged to be married was told by his fiancee that she did not want to see him again. In addition, he was told that he was not to see his child by her again. This particular case proved to be a very frustrating one. At first, the patient seemed to be responding to counseling and then he was told he was being boarded out of the Navy. This, in addition to the previously mentioned problem, caused him to start drinking heavily and rejecting all support that was offered to him.

Another common fear which picks up on the secondary problem of the patient just mentioned, is the chance of being boarded out of the Navy. These individuals do not seem as concerned about having HTLV-III as they are about losing their income and not being able to support themselves. This is especially true of the E-3 or E-4 who for the first time has had a steady income and has bought a new car. They fear not only losing their income, but also the possibility of not finding a civilian job because of the early discharge from the Navy, and the repossession of all their worldly goods because they cannot afford to pay off the debts they have incurred. A big fear at first, but one I do not hear too often now, is the fear of death. Initially, all those admitted for HTLV-III were afraid they would soon die. I counseled with them that death was not imminent with this virus. I also spoke with them of the possibility of this progressing into the AIDS disease and of their fears about what could happen to them if this should occur. In speaking with them, I advised them that a lot of information is not yet known and they should read what they can on HTLV-III/AIDS and to ask the doctor for any information he can give about their cases.

Another fear that has been expressed by a few of the patients is the fear of physical harm from shipmates if they find out they have HTLV-III. I have advised them that the chances of this happening are very slim, unless they themselves tell others that they have tested positive for HTLV-III. SECNAVINST 5300.30 states in paragraph 6: "HTLV-III test results must be treated with the highest degree of confidentiality and released to no one without a demonstrated need to know." If others do find out, any threats or physical violence should be reported to superiors or the Master-At-Arms Force.

The concept of denial is in contrast to the feelings of fear. Patients who refuse to accept the fact that they are carrying the HTLV-III virus state they are feeling fine and do not know why they are in the hospital. In cases like this, I continue to minister to the patient and let them know that I care and am available to help in any way I can.

## Ministering To An AIDS Patient

One case involving my ministry to an AIDS patient was paradoxically both depressing and fulfilling. It was depressing because I was present to watch the patient die a painful death, and fulfilling because the patient experienced a spiritual reawakening and turned to God for strength and forgiveness. Many hours were spent dealing with the patient's past seeking the reassurance that God is a forgiving God and that a better life awaited him. The assurance of God's love and forgiveness and the gift of life buoyed this patient's spirit so that he would often speak of the new life that would be his. The patient seemed to make a special point of holding my hand when we prayed—perhaps to feel in a tangible way the presence and love of God. I feel that this touch, as well as daily ministry of presence and the Word, helped this patient enjoy his last weeks and led him to the eternal life God offers us.

## Group Therapy

Group therapy is provided for HTLV-III patients on almost a daily basis. The social work, pastoral care, and medical departments work together to relate to the patients upon admission and discharge from the hospital. An "alumni" group session is being discussed and supported by the HTLV-III patients. These group sessions help HTLV-III patients reach out to each other for mutual support because they feel more comfortable expressing fears and concerns in a group setting where there is no fear of ridicule or rejection. The group has also made them more receptive to my ministry during my rounds on the floor.

## Ministering To The Patient

In ministering to HTLV-III/AIDS patients, I must remember that each patient is a human being with different emotional and spiritual needs. There is no set format for counseling and speaking with an AIDS patient; I approach each as I would any other patient, hoping they will be open with me. I must be ready to be a sounding board for those who wish to express feelings of frustration and helplessness regarding their problems. I may become their confessor as they seek the words of assurance and forgiveness which I can convey to them.

In contrast, I have also found myself rejected because the patient feels a chaplain is not needed, or because the patient has built a barrier to protect against the rejection of others. In response to this reaction, I provide a daily ministry of presence to let them know I care. In this way they may open up, and I will have a chance to minister to them. In dealing with these patients, I again emphasize the point: do not treat them as lepers in biblical times who were kept at arms length. They need to be ministered to the same way as other patients in the hospital with a ministry of presence, care, and concern offering God's grace through the words of prayer and of the sacraments.

# AIDS And The Martyrs Of Memphis

## An Alternative To Fear

**R. Stephen Powers**

No disease so strikes terror and fear into people's hearts like the current epidemic of Acquired Immunodeficiency Syndrome, AIDS.[1] Since its discovery and diagnosis in 1981, the epidemic of AIDS has grown to affect 32,000 lives in this country.[2] The total number of people infected with the HIV, most of whom will develop AIDS, is five to ten million.[3] Because AIDS is usually sexually transmitted, and because Americans are, despite the danger, sexually promiscuous, the projected growth of this disease is staggering.[4] There is no known cure for AIDS; there is no vaccine; and there are no survivors in the battle against it. Without education or without thinking to care, most people respond to the disease and to those who have it with fear.

At an AIDS Symposium, the Reverend Canon Frank Cooper, IV, Canon Theologian at Saint Mary's (Episcopal) Cathedral, Memphis, Tennessee, said:

> This fear causes us all to quake and do some very thoughtless things. To look for the transmission of

[1] I wish to thank the Reverend Canon Frank Cooper, IV, Canon Theologian at Saint Mary's Cathedral, Memphis, Tennessee. It was his sensitive and thought provoking sermon which started my own thinking in this direction.

[2] Thomas C. Quinn, M.D., "The Global Epidemiology of the Acquired Immunodeficiency Syndrome," *Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families*, (April, 1987). 7.

[3] Ibid.

[4] Ibid. By 1991, cases of AIDS will have grown from 32,000 to 270,000.

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> AIDS in the most bizarre and unlikely of places—mosquitoes, chalices, persons we suspect of promiscuity, those we like, those we don't like, those we don't know.[5]

AIDS is a terrifying spectre; for those who have it and for those who wish not to catch it.

Yet neither epidemics nor fear are new. In 1878, little more than a hundred years ago, an epidemic of yellow fever swept through the mid-south. Though others areas of the country were affected, it was Memphis, Tennessee, that was most severely hit.

This article traces the epidemic which struck the city of Memphis in 1878, details the response of Sister Constance and her companions to sickness and to the fear of contagion, and draws some parallels between the epidemic of 1878 and the epidemic in 1988. By looking at how others have responded in times of epidemic and fear, we may gain insight and guidance for our response to AIDS in 1988. The path we walk with AIDS has been trod by others before us.

## The Feast Of The Martyrs Of Memphis

The Episcopal Church at General Convention in 1985 entered a day, September 9th, in its liturgical calendar commemorating "Sister Constance and her Companions: the Martyrs of Memphis." [6] While other churches had their victims and martyrs in the yellow fever epidemic, only the Episcopal Church has made their memory a matter of liturgical commemoration.[7]

## MEMPHIS, 1878

In 1878 Memphis was a lively, vibrant river town of 47,000 with the rowdiness and corruption that comes from mixing commerce and the seas.[8] Saint Paul, who did so much work in the ancient port city of Corinth, would have felt at home in Memphis with its churches, synagogues, businesses, bars and brothels.[9] The city was growing, business was good, and the future looked bright.

[5] The Rev'd Canon Frank Cooper, IV, "AIDS & the Martyrs of Memphis," an unpublished sermon delivered on September 9, 1987 at Saint Mary's Cathedral (Episcopal), Memphis, Tennessee.

[6] *Journal of the General Convention of the Episcopal Church* (New York: Church Hymnal Corp.).

[7] Sr. Jean Deblois, "Responding to AIDS in West Tennessee," *Church News*, Vol. II, No. 6 (Oct. 1987), 3. St. Peter's Church (RC) lost at least four priests and the Roman Catholic order of Saint Joseph of Corondlet lost eight nuns.

[8] Lawrence Buser, "City Still Bears Scars of Epidemic Century Ago", *The Commercial Appeal*, June 18, 1978, B1.

[9] Franklin M. Wright, "A Brief History of The Martyrs of Memphis," *Service Bulletin for the First Commemoration of Sr. Constance and her Companions at Saint Mary's Cathedral. September 9, 1987,* 11-17. Annie Cook, who ran a brothel in

> Before the epidemic, Memphis was a cosmopolitan city with a diverse foreign population. There was constant river and railroad traffic and the city was the cotton capital of the world." [10] Dr. Charles W. Crawford, associate professor of local history at Memphis State University, says, "It could have grown into a southern Chicago if things had turned out a little differently".[11]

Because of corruption in the city government, Memphis lacked even the most basic of sanitary provisions. Sewage flowed openly in the muddy streets.[12]

> Unsanitary tributaries snaked through the city and drinking water came from defecation cisterns and wells. Health codes did not exist and, at the peak of the fever outbreak, it seemed that soon, neither would the city.[13]

Previous outbreaks of yellow fever in 1828, 1848, 1855, and 1873 had warned the city. In 1873 outbreak, five years before the major epidemic, 2,000 were killed.[14] The warnings went unheeded.

## Yellow Fever

Yellow fever is caused by the bite of the female *Aedes Aegypti* mosquito. Once the mosquito bites a person who carries the yellow fever virus, the mosquito carries the virus to all subsequent people who are bitten. Mimi White, a Memphis writer of the period, gives a graphic account of what it was to contract "Yellow Jack."

> Of the serious cases, nearly half end fatally, the initial onset of fever being followed by a few days' remission before the terrifying phase in which the patient becomes jaundiced, often wildly delirious and vomits great quantities of blackened blood which has seeped into his stomach by internal hemorrhaging. Within 48 hours

Memphis, became a community heroine for her efforts to fight the fever. After sending her "girls" to safety and opening her establishment as a hospital, she died.

[10] Buser, B1. The shield of the Naval Air Station, Memphis, still has a cottonball on a crown as its central symbol.

[11] Ibid.

[12] Mimi White, "Yellow Fever," *The Commercial Appeal*, (Oct. 31, 1978), A2. "Even in an age of low public expectations in matters of municipal charm, Memphis was repulsive, 'Cologne, that European city of a thousand disgusting smells, backs down before Memphis' wrote a visitor from North Carolina in 1867."

[13] Buser, B1.

[14] Perre Magness, "Epidemic End Was Cause to Celebrate," *The Commercial Appeal*, (Nov. 26, 1987), D2.

> most are dead. Those who survive enjoy lifelong immunity and, amazingly, no permanent after effects.[15]

Like AIDs, there is no known cure for yellow fever. Like AIDS, no one knows its origins. Like AIDS, yellow fever brought a horrible death to many of its nineteenth century victims. (Unlike AIDS, yellow fever was not *always* fatal).

Twenty two years after the epidemic in Memphis, an Army physician working in Cuba named Walter Reed was to discover the connection between the species of mosquito and yellow fever and to develop a vaccine against the disease.[16] But in 1878, no one knew the connections, the causes, or the cure. People were dying. People were afraid.

## Memphis, 1878

In the hot, mid-South summer of 1878, the city of Memphis was concerned about yellow fever. Rumors of an outbreak in New Orleans turned concern into fear.[17] Memphis city officials, fearing the economic effects of quarantine, denied reports of the fever. But people upriver had a right to be concerned, for indeed the Fever had hit New Orleans.

> All summer long, rumors of yellow fever in New Orleans had set Memphians on edge. Then, at the first of August, it was reported that a steamboat hand named William Warren had been moved from the City Hospital into quarantine, where he had died. Soon more cases were reported daily, and the population was in a panic.[18]

Within 48 hours after Warren's death fifty-five persons were dead, and the panic was on. Historian J. M. Keating, writing in 1886, remembers this fear and panic.

> (It) deadened all human sympathy, all the kindlier emotions of the human heart, all kinship, all regard for neighborly claims, and in a few cases all natural affection . . . The future, which only a few days before looked so bright, was overshadowed by a pall and was forgotten in the presence of the pestilence . . . Men, women, and children poured out of the city by every possible avenue of escape.[19]

Travel agents fared well in the panic as 25,000 of the city's 47,000 fled up river. Of those remaining, some 17,600 persons contracted the

[15] White, A2.
[16] White, 2A.
[17] Ibid., 3A.
[18] Magness.
[19] Ibid.

disease.[20] Between 5,000 and 6,000 persons died. The city was bankrupt and later forced to give up its charter.

> This fear caused most Memphians to react as though a great army, bent on annihilation, was descending on the city. Businesses shut down in mid-day, men hearded their families together and headed for the railroad depot, leaving all their worldly goods behind except what could be quickly crammed into valises. Dinner was left uneaten on the table, laundry on the line, horses and household pets abandoned . .
> Wild scenes ensued in which Victorian amenities were forgotten as men shoved women and children aside to board trains so jammed that passengers rode hanging out the windows . . . When it seemed no more could possibly get on, latecomers would board anyway, drawing pistols if anyone challenged them.
> The exodus was just as frenzied on the dirt roads . . . [21]

Reading these descriptions, one can feel the fear which must have clutched the hearts of these people. People who were simply going about their daily lives were suddenly confronted with an enormous threat: unless they protected themselves immediately, they would die. An unknown and deadly disease stalked the city. No one knew how to defend against it. Those who were financially able did the only sensible thing to protect themselves and their families: they ran for their lives.

## The Roll Call of Martyrs

There were those, the "Martyrs of Memphis," who were not "sensible," and who suffered and died for the love of God and his people. They were nuns, priests, and laypersons. Although more is known about some of the martyrs than others, a "roll call" of the martyrs, according to the date they died, may be helpful.[22]

**The Reverend Charles Carrol Parsons**
**Age 40**
**Rector, Grace and Saint Lazarus' Church, Memphis**
**September 7**

The Reverend Mr. Parsons, as a priest, undertook the task of providing what Navy chaplains call "deckplate ministry." He was

[20] Buser. One railroad ticket agent sold $35,000 in tickets in three days.

[21] White, A7.

[22] Wright, "A Brief History." All information in this section taken from this source unless otherwise noted.

present to the suffering an dying to give comfort, prayer, Scripture reading and the Sacraments; he was present to commend the souls of the departed into the gracious hands of God; he was present to bury the dead and to help the living to go on living.

Prior to his ordination, Charles Parsons was graduated from the United States Military Academy and appointed a Second Lieutenant in the Fourth Artillery, in 1861.[23] He served the Union Army during the Civil War, was promoted to Captain with the brevet of Lieutenant Colonel. In 1868, he was ordered to West Point for instructor duty. It was at West Point that he began to study theology, and he was ordained deacon, and subsequently priest, in 1870. At the time of the epidemic, he was rector of Grace and St. Lazarus' Church. In Memphis, he continued his military involvement as a "Reservist" chaplain to the Chickasaw Guards.[24] Having faced death in the service of his country, he was to again face death in the service of his Lord.

**Sister Constance, Community of Saint Mary (CSM)**
**Age 32**
**Died September 9**

Eight (Episcopal) nuns from the Community of St. Mary, whose Mother House was in Peekskill, New York, served in Memphis at the time of the epidemic. Sister Constance was the superior of the convent and directed most of the relief work conducted by the sisters. When the outbreak of yellow fever occured Sister Constance and Sister Thecla were in New York visiting the Mother Superior of the Order. While thousands were fleeing Memphis by every means available, the sisters immediately left the safety of New York and returned to Memphis to minister to the sick and dying.

**Miss Waring, Volunteer Nurse at Canfield Orphan Asylum**
**Age unknown**
**Died September 11**

**Sister Thecla, CSM**
**Age 38**
**Died September 12**

Sister Thecla returned with Sister Constance to Memphis. Both were struck with the fever within hours of each other.

[23] Franklin M. Wright, "The Sisters of St. Mary at Memphis," *Extract* (New York: 1879), 26.

[24] Ibid., 26.

**Mrs. Bullock, Widow, Sisters' Matron**
**Age unknown**
**Died September 16**

**The Reverend Louis Sandford Schuyler, priest,**
**Age 26**
**Holy Innocents' Church, Hoboken, New Jersey**
**Died September 17**

The Reverend Mr. Schuyler was a young man with a passion to serve God and his Church. He had been offering the Eucharist for the sisters at Saint Gabriel's Chapel for the Community of Saint Mary, Peekskill, New York, for some time when he heard of the death of Mr. Parsons in Memphis. When he learned there was no priest to minister to the sick, he immediately volunteered to go. His parting comment to those in Peekskill who were concerned for his safety reflects the man and his intentions: "Why do you regret my going? God calls me; I am safe in His hands; he will do what is best for me."[25] He was to last only four days in Memphis. He caught the fever and died on September 17.[26]

**Sister Ruth, CSM**
**Age 28**
**Head of the Canfield Orphan Asylum**
**Died September 18**

Sister Ruth carried on after the others died. Her letters to the Mother Superior gives a rare, eye-witness account of life in an epidemic.

**Dr. William James Armstrong**
**Age 38**
**Attending physician**
**Died September 20**

Dr. Armstrong worked directly with the sisters, provided whatever medical care he could, while educating and directing the volunteer nurses.

**Mrs. Scherrie, Widow and Volunteer Nurse**
**Age unknown**
**Died September 23**

[25] Ibid., 55.
[26] Ibid., 28-29.

**Sister Frances, CSM**
**Age 27**
**Head of the Church Home**
**October 4**

These martyrs were a varied and commonplace lot. They were mostly young and "had their whole lives ahead of them." In the fall of 1878, there were even those who criticized the martyrs for "senselessly" throwing their lives away.[27] Why, for the love of God, would they volunteer to suffer and to die so young? Was it not a sin to be so reckless with God's good gift of life? Why add waste upon tragic waste? But the martyrs who went to Memphis were not just social workers. They went because God called them. It was that simple for them.

## Life In The Midst Of Death

The late summer of 1878 was a tragic time for Memphis. With the fever raging, death was a certainty for anyone remaining. After a state of quarantine was declared, the inhabitants were kept in Memphis at gunpoint.[28] The rest of the country could not afford to let the fever spread; it had to run its course in Memphis. For weeks, there was nothing to do but give comfort to the sick and bury the dead.

In a letter to the Bishop of Tennessee, dated September 1, Mr. Parsons wrote:

> Friday I was called to see, at the Whitemore House, a sick family consisting of a mother and two children. I drove there as quickly as possible. They were bringing downstairs the remains of the son. In a little room at the head of the stairs the faithful Mobile nurse had composed the body of the little daughter in death, and on the bed hard by, the mother was breathing her last . . . My dear Bishop, the situation is indescribable.[29]

The epidemic in Memphis garnered world-wide attention. Everyone wanted to know how things were progressing; but with the city under quarantine, not even a reporter wanting a "scoop" would venture into Memphis. Mr. Parson's frustration is evident when he writes:

> People constantly send to us, saying, "Telegraph the situation." It is impossible. Go and turn the Destroying Angel loose upon a defenseless city; let him smite whom he will, young and old, rich and poor, the feeble and

[27] Ibid., 57.
[28] White, 7A.
[29] Wright, *Exerpts*, 22.

> the strong, and as he will, silent, unseen, and unfelt, until his deadly blow is struck . . . [30]

The Sisters of St. Mary nursed the sick, supervised the volunteer nurses, and ran the orphanages. With many parents dying, the orphanages were overflowing. Their problems were compounded because they could not admit a child until they medically determined if the child were contagious. After Sr. Constance died, Sr. Ruth found even the administration of the convent and the relief work was an overwhelming work.

Of the nuns, Mr. Parsons wrote:

> The sisters are doing a wonderful work. It is a surprise to see how much these quiet, brave, unshriking daughters of the Divine Love can accomplish in efforts and results.[31]

Of course, it was not only the martyrs themselves who displayed courage. There were countless others who "did their duty," even at peril to their own lives. One of the sisters describes one such example:

> I shall never forget the countenance of one of the two gentlemen—I think both were physicians—who carried the girl from the carriage up to the ward; it was so expressive of terror and dread that it made me admire him all the more for doing his duty.[32]

## No Plastic Saints

One of the dangers in writing about martyrs, of course, is the tendency to make "plastic saints" of them. That is, to portray them as heroes without fear, rather than heroes who, by the grace of God, overcame their fear and served God to the point of death.

The truth is the epidemic broke their hearts with its senseless suffering and death, and then it killed them. Almost overcome by the enormity of the suffering, one of the sisters says,

> I remember feeling, for a moment, almost overcome with heart-sickness, as I saw some go away with the unsatisfying promise that the Sisters would come to their dying ones the next day, one day too late. . . . The sisters had made more promises than they had time to fulfill. . . . Oh, it is heart-breaking! One can do so little.[33]

[30] Ibid., 22.
[31] Ibid., 24.
[32] Ibid., 24.
[33] Ibid., 24-25.

Once the dean of Saint Mary's Cathedral, the Very Reverend George C. Harris (One who caught the fever, but who survived.), said to Sr. Constance:

> You are attempting too much. You must desist. If the fever strikes you in this condition you will be sure to die. Go home.

Sr. Constance replied.

> No, I shall go on as I am. I shall do my duty, and I would do it if I knew certainly the result would be as you say. I would gladly die to save the patient's life.[34]

A similar determination was shown by Sr. Ruth. After Mr. Parsons had died, and after Sr. Constance and Sr. Thecla contracted the fever, she had a few moments to ponder her own mortality and whether or not she had done the right thing in staying:

> I do not fear the fever, but I know we shall all have it. The only ray of sunshine is, that it was right to come; and we are here; so we go on with tired but thankful hearts.[35]

A few days later, they were dead. The fever continued to ravage Memphis until October 18, 1878, when an early frost killed the mosquitoes.

## A Meditation On Fear

There are several common denominators between the Martyrs of Memphis and those who face the AIDS epidemic today. Both face a deadly disease with no known cure. Both diseases involve terrible suffering and death. And there is the obvious link between 1878 and 1988—the reaction of people to the threat of death: fear.

It is a normal, human reaction to be afraid. Anyone who claims not to be afraid of AIDS is no saint or martyr, but a fool. But it is one thing to experience the natural human emotion of fear, and another to base all responses on that emotion. The Martyrs of Memphis show us another response to suffering and fatal disease.

Canon Frank Cooper, in a sermon commemorating the Martyrs, says, "Martyrs are those people who fill the gaps left by fear in the life of a Christian community." [36] AIDS, and the fear of AIDS, is leaving many gaps in our society. Persons with AIDS are "excommunicated" from society, the military, and even from the

[34] Ibid., 14-15.
[35] Ibid., 32.
[36] Cooper.

Church.[37] Newspapers and magazines report persons with AIDS who are forced out of their local churches. Children with AIDS (a horrifying aspect of the disease) [38] have to go to court to win back the right to attend classes in public schools.

The fear of AIDS is making many gaps in our society. It is these gaps, created by fear, that the religious community, and miliary chaplains are called to fill. In so doing, those who suffer will not suffer alone, but will know the compassion of true religion.

It is not enough, as some people suggest that we get over our fear of AIDS. Fear of AIDS is normal and natural. How does one "get over" the fear of catching a disease in which one dies a slow, lingering and painful death? [39] Are we to pile guilt (for not having "got over" our fear) on top of fear itself?

It is more helpful to look to the Martyrs of Memphis for inspiration. They, too, were afraid. But their love for God was greater than their fear of death. That love of God, and the sense that they should obey the call of his Son to lay down their lives sustained them through the horror; it enabled them to rise above fear; and it helped them to "give their fear . . . to God." [40]

The gospels record Jesus' demand that we "pick up our cross, and follow him" (*Mt.* 10:38, 16:24; *Mk.* 8:34; *Lk.* 9:23, 14:27). The reality of "picking up the cross" and laying down our lives in battle is a prospect that confronts every military chaplain. We have had many chaplains to die in the line of duty, providing spiritual care to their flock. Will military Chaplains fill in the gaps caused by the fear of AIDS? Will we provide the leadership expected of us by loving God and the sick more than we fear AIDS? Allowing our lives to be dominated by fear will paralyse us and cause us to betray the religion and faith we profess. Love of God, and hope in eternal life, will enable us to overcome that fear, and to respond with compassion to those who suffer. Our lives and our service are governed by fear or freed by love.

We are at the beginning of the worst epidemic to strike western civilization since the Black Plague destroyed one-third of Europe in the fourteenth century.[41] AIDS has already infected and killed more than were killed in the Yellow Fever epidemic in Memphis

[37] John Snow, *Mortal Fear: Meditations on Death and AIDS,* (Cambridge, Mass: 1987), 6.

[38] The best and most recent study is the Surgeon General's Report, listed in the Bibliography.

[39] Amalie Weems, in *Church News*, 3.

[40] Cooper.

[41] Elisabeth Kubler-Ross, *AIDS: The Ultimate Challenge* (New York: Macmillan Publishing Co., 1987), 318. Speaking of the fear and prejudice that AIDS generates, Dr. Kubler-Ross says, " . . . as far as AIDS is concerned, most of us are still in the Dark Ages."

in 1878. Yet this difference is one of degree, not of kind. The natural response to both is fear.

By learning how the Martyrs of Memphis responded in their day, perhaps we, in our time, can learn to make the same response. If we in our own day, and as military chaplains, have the love of God they did, then we too will find that "perfect love casteth out all fear" (I John 4:18). Fear is contagious; but so is Love.

## Collect for Sister Constance and Her Companions

## The Martyrs of Memphis

> We give thee thanks and praise, O God of compassion, for the heroic witness of Constance and her companions, Martyrs of Memphis, who, in a time of plague and pestilence, were steadfast in their care for the sick and dying, and loved not their own lives, even unto death: Inspire in us a like love and commitment to those in need, following the example of our Saviour Jesus Christ, who liveth and reigneth, one God, world without end. Amen.

Sister Constance and your companions, watch and pray for us.

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# Book Reviews

*Pastoral Care As Dialogue*

*Joachim Scharfenberg (Translated by O. C. Dean, Jr.)*

Fortress Press,

Philadelphia, PA, 1987

Softcover, 141 pages

Joachim Scharfenberg is a professor in the institute for Practical Theology, Christian-Albrechts University, Kiel, West Germany.

Scharfenberg's purpose is to demonstrate the need for "dialogue" as opposed to "proclamation" in pastoral care. The translator states it well. "Theologically, the aim is not just to proclaim God's Word but in and through the counseling process to help the dialogue partner apply its liberating power to his or her life." To defend this thesis Scharfenberg puts forth a cogent argument from a multidisciplinary stance. He draws from linguistics, philosophy, depth psychology and quantum physics in just the first chapters.

Scharfenberg then analyzes the basic forms of dialogue and classifies them according to the relationship of the partners. He proposes that the pastoral dialogue, rather than being a special case, is the application of all four forms oriented towards a helping relationship. He goes beyond polemic here to give some practical guidelines for the establishment of the helping relationship. He explores the interpersonal dynamics in dialogue and some specific issues that a pastor should address in self-examination. "Why do I feel myself drawn so strongly toward the spiritually weaker person?" "Why must I always be so nice to everyone?" "Why am I actually so legalistic in my dialogues?" He calls on pastors to scrutinize themselves as well as the relationship.

Finally he looks at series of dialogues. For Scharfenberg "a series dialogues lasting over a longer period of time is called counseling." He gives an excellent analysis of the issues and dynamics for establishing ongoing counseling. He also differentiates counseling from care and support by viewing all counseling as "conflict counseling."

This is a thought provoking and insightful book that has much to offer the American reader. Although at times slow reading due to the pedantic style, it is worth the work. Intended originally for a readership well-versed in the modern theology and scholarship of Germany, it is at times abstruse but it is nevertheless relevant to American pastors. It forces dialogue as it is read. It is worth reading, but more importantly, it is worth thinking about.

Chaplain (CPT) Robert Nelson
USA

***AIDS: The Ultimate Challenge***

Elisabeth Kubler-Ross

Macmillan Publishing Company, 1987

Hard cover, 329 pages, $17.95

Elisabeth Kubler-Ross was born in Zurich, Switzerland and attended medical school there at the University of Zurich. She is a psychiatrist and authority on death and dying. Among her previous best sellers are: *On Death and Dying, Questions and Answers on Death and Dying, Death: the Final Stage of Growth*, and *To Live Until We Say Goodbye*. She now makes her home at Healing Waters Farm in Head Waters, Virginia, site of the Elisabeth Kubler-Ross Center.

Elisabeth Kubler-Ross finds that her work with AIDS victims is a natural outgrowth of her work in death and dying. She says " . . . we can no longer deny that AIDS is a life threatening illness that will eventually involve millions of people and decimate large proportions of our human population, it is our choice to grow and learn from it, to either help the people with this disease or abandon them. It is our choice to live up to this ultimate challenge or perish."

In this latest book, she chronicles her fight on behalf of the victims of this tragic scourge. In the first three chapters she writes of her work with AIDS patients and the inhuman treatment to which many are subjected. Chapters four, five, and six describe her efforts to establish a nursery on her farm in Head Waters, Virginia, for abandoned babies with AIDS. The struggle was unsuccessful at this writing because of the hysteria among local residents to any mention

of the word, "AIDS". In chapters eight and nine, she provides case studies of women who are infected with the disease and interviews with male AIDS victims. In the latter part of chapter eight there is a letter written to a male friend from a minister. This letter was well worth the cost of the whole book. There is such caring, compassion and comfort found there. Chapter nine is written by a disciple of Dr. Ross who writes of her experiences with dying AIDS victims in the San Francisco Bay area. Her experiences with these socially outcasted patients were heart wrenching and deeply moving. Chapter ten covers AIDS in our nation's prison system. There is an epilogue where the statistics of the epidemic and a cry for action are found.

I found this book to be in many ways like the crisis that it reports. The first half was disjointed and without any direction. In the latter half of the book, however, is where the cream of this work is to be found. I personally learned much from this work and would recommend it as an excellent reference on the human issues involved in the AIDS crisis.

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***Mortal Fear: Meditations on Death and AIDS***

John Snow.

Cowley Publications,

Cambridge, Mass. 1986.

92 pages. Paperback $6.95.

The author is Professor of Pastoral Theology at Episcopal Divinity School in Cambridge, Mass.

Professor Snow's book is prompted by a series of personal events which he sees as having significant parallels in the world of politics, science, technology and health.

Part one, "Mortal Fear," contains five meditations on AIDS delivered at a provincial conference for Episcopalians. The meditations focus on AIDS as a disease, as a reminder of our mortality, as a fatal disease, as a definition of our humanity, and as a disease that leads us to a new appreciation of God.

Part two "Mortal Concentration," is comprised of rambling thoughts about the author's colon surgery, President Reagan's similar medical procedure, his article on the Mafia, the surgical military strike against Lybia, the failure of salvation through technology, the

Challenger accident, the Chernobyl nuclear accident, nuclear war, patience, pain, and the language of death. This section has more the quality of a writer's journal than a cohesive piece of work on death.

The author's thesis throughout the meditations is: "Until we come to grips with our mortality, learning to accept it without denial or despair, until we can fit death into a larger pattern of thrustworthy corporate life that provides continuity from one generation to the next, the human enterprise is doomed to the consequences of its own aimlessness."

There is much in *Mortal Fear* to recommend it. The ideas as provocative, clearly expressed, and relevant to the world in which we live and provide ministry. Some things about the author's style are annoying, however. He tends to state things in paradoxical hyperbole. Examples: "Worship is the most useless of all human enterprises, and consequently the most free." " . . . [T]hose whose primary concern is their survival spend their lives in slavery to the devil." "Without the death of the autonomous ego in the disintegration of mortal fear, there will be no resurrection." This habit detracts from the work.

Chaplain (LTC) William L. Hufham
U.S. Army

***Good-Bye I Love You***

Carol Pearson

Jove, 1986

I am a nurse; I am a mother; and I am the wife of one who has AIDS. Three demanding roles that I play daily trying desperately to survive all. I have talked with psychiatrists, chaplains, physicians and read many articles dealing with the subject of AIDS, but none has moved me or helped me as much as Ms. Pearson's book, *Good-bye I Love You.*

It took me two weeks to read the book because I had become very fed up with the subject, and it was easier to deny the problem. I read the first 15 pages and decided I just couldn't deal with it. I put the book down, but two weeks later I picked up the book and started to read it again. This time I could not put the book down until I had finished it.

Ms. Pearson's book helped me get in touch with my own feelings. I had so often wondered how I could still love this man who had done these things to me. How could I love someone who had caused me all this heartache—was I crazy? Was I the only one who lived with this shame and fear? Why? But when I felt her hurt, I felt

my hurt. Her pain was my pain and her love for Gerald was the same love I feel for my man. I knew that I could still love him, support him, and care for him. She helped me find me, and let *me* be. I found her a unique and beautiful person and in some curious way therefore so was I. I could believe in myself and the love that I had tried to deny. The nurse in me wants to go out and help the cause. To teach and support others, both patients and their families. What Ms. Pearson did is what I feel will help halt the deaths of some AIDS patients. Love and support are the most important medicine that we can give them. Loneliness kills.

I sincerely recommend this book to those who have AIDS and to those who love and care for them.

Reviewed by an Army Nurse

***Blessed Are the Persecuted:***
***Christian Life in the Roman Empire, A.D. 64-313***

Iuo Lesbaupin
Robert R. Barr, translator.

Maryknoll, New York: Orbis Books, 1987.

98 pages, $16.95

Robert R. Barr brings the first English translation of Iuo Lesbaupin's Blessed Are the Persecuted, originally published in 1975. The book is a brief, but excellent, study of the persecution of the early martyrs, and a theology of persecution as well.

Lesbaupin presents the history of the early Church as it developed in reaction to the persecutions by the Romans. During the period from the life of Christ to the Edict of Milan, Lesbaupin estimates that more than 100,000 Christians were martyred. Christians lived peacefully with the Romans until the fire of 64 A.D. which destroyed Rome under Nero's rule. From then until 313 when Galerius was forced to issue an edict acknowledging the " . . . uselessness of the persecution of Christians because of their unflagging resistance."

Christians were persecuted for a number of reasons. Their religious customs were viewed by the Romans as inhumane, e.g., cannibalism and infant sacrifice. Also their refusal to perform pagan rituals increased hostility towards them. Finally, according to Lesbaupin, once a clear distinction appeared between Judaism and Christianity, the Romans then perceived Christianity as a new religion which threatened the state. Lesbaupin discusses these reasons for

persecution in light of the legislative actions taken by the major Roman emperors: Nero, Trajan, Hadrian and Diocletian.

In addition, Lesbaupin develops a theology of persecution resting upon the power of the Christian witness. The martyrs who put down their lives for their faith led, in turn, to the Apologists. " . . . Never give up on anyone who has fallen," was the rallying cry of the early Christian community when under siege from their Roman persecutors. In the last third of his book, Lesbaupin's comments on the book of Revelation's forecasts of the final victory of good over evil as a message of hope for modern Christians as for primitive Christians.

For students of early Church history, for those who look to the early martyrs for inspiration, and for those who today face persecution for their Christian beliefs, Lesbaupin's book will provide both historical perspective and spiritual guidance.

Paul F. Bauer, Th.D.
North East, Maryland

*The Intimate Connection—Male Sexuality, Masculine Spirituality*

James B. Nelson

Westminster Press, Philadelphia: 1988

Paper, 136 pages, $8.95.

James B. Nelson is Professor of Christian Ethics, United Theological Seminary of the Twin Cities.

*The Intimate Connection—Male Secuality, Masculine Spirituality* is about male journeys into a spirituality that is defined as " . . . basic life patterns and the way we express them . . . the embracing of the life of the flesh."

The author lays a foundationl argument that is at a minimum both Christologically and sexually different from accepted formulae. Jesus' uniqueness lay not in having two natures, one divine and one human, miraculously combined. Rather, he possessed the same human nature we all have, yet remarkably open in mutuality with God's loving power. Thus, in a less patriarchal age, the paradigmatic Christ might well have been female. What remains is a Jesus " . . . who did not understand himself to be ontologically different from other human beings."

Using abstract interpretations at several levels, the author leaves the reader struggling to make intellectual leaps to follow the pattern of reasoning. The results read like a feminist manifesto. The

author's theological premises argue for an erotic transformation in our ways of thinking and call for a view of life as mutual and participatory. "An erotic consciousness bears the promise of the sensuous body-self making love with the earth . . . two knowers and two knowns reveal(ing) their connectedness."

Therefore we are now freed for sexual prayer and can offer thanksgiving for "grateful delight in our own self-pleasuring possibilities (the author's euphemism for masturbation) . . [and] find new gratitude for the erotic desires we have felt and for their divine source." We may also shed old stereotypes and "embrace homosexual persons who symbolize positive, exhuberant sexuality."

Nelson aggressively assaults any ideas that smack of traditional or non-feminist values. He calls for repentance of any who consider that we are not complete in ourselves. Karl Barth, with his views that homosexuality is perversion and idolatry, is among those who draw the author's fire.

For the chaplain community, this book could serve as a primer in current androgenous theology. This reviewer was disappointed that a book with such an appealing title as *The Intimate Connection—Male Sexuality, Masculine Spirituality* had such a radically narrow field of vision.

Chaplain (MAJ) Harvey R. Brown, Jr.
USA

***Approaches to Auschwitz: The Holocaust and its Legacy***

Richard L. Rubenstein and John K. Roth

Atlanta: John Knox Press, 1987

There are no comfortable ways to approach Auschwitz—neither the death camp itself, nor the horrors for which it has become a metonym. This book, jointly written by a Christian professor of philosophy (Roth) and a Jewish professor of religion (Rubenstein), brings into a single volume a variety of viewpoints on the Holocaust, but it does not allow religion, history, or philosophy to create a comfortable intellectual distance between the reader and the murders of six million Jews and nine million other victims before and during World War Two.

The authors trace the historical sources of the Holocaust from its roots in the arrangement between the rabbis of the first century, CE, and the Roman rulers. The Jewish people would surrender the sword and "create a religious culture predicated on the disciplined renunciation of the use of force." (page 37) This arrangement

permitted Jews to play important roles in Europe and elsewhere for centuries. The authors trace the changes in social and economic structures in Europe which opened the way for Hitler and the Nazis to create a powerful, efficient, and economical system for genocide.

Changing economic and social conditions gradually deprived Jewish people of the cultural roles they had played for so long in Europe. These same changes created pressures on other groups; in the growing economic struggles, the Jewish people were increasingly regarded as "a surplus or redundant population." (page 5) At the same time, generations of religious dissonance allowed the Jews to be defined as outside the sphere of ethical or religious obligation. Rubenstein and Roth cite another Holocaust scholar, Raul Hilberg: "The missionaries of Christianity had said in effect: You have no right to live among us as Jews. The secular rulers who followed had proclaimed: You have no right to live among us. The German Nazis at last decreed: You have no right to live." (pages 9-10)

The authors move back and forth between the painfully particular stories of victims and perpetrators and the gruesome general descriptions of the theory and practice of genocide. It is startling to read that none of the orders which led to so many deaths were illegal at the time; Hitler's orders were law. It is disturbing to be encouraged by the fact that the gas chambers, in addition to being so much more efficient, were developed in part because the people who were ordered to line up Jews and shoot them individually eventually began to have trouble executing their orders. It is sobering to learn that Jewish resistance could not be sustained because resistance movements require support in the general population, and there were very few places that afforded such support to Jews.

The last section of the book describes some responses to the Holocaust. The responses of religious institutions and the various professions and business leaders during the years of death, and the theological, literary and philosophical responses afterward, lead to questions about the meaning of the Holocaust in history, and the question of the meaning of history after the Holocaust. As the authors note in their Preface, "Such enormous destruction can drive to despair those who try to comprehend why darkness has such power."

Religious leaders in all traditions, but especially in this case, Christians, need to pay close attention to the religious dimensions of the Holocaust. There were, after all, persons who resisted genocide; we need to know what moved them to their special heroism. Even more importantly, we need to know why others were not so moved. And if we would not personally approve murdering persons of different religious faiths from our own, perhaps we should give

serious though to this dark history, to ponder how intolerance of religious beliefs and practices played such a powerful role in the "final solution."

There is much to be learned from this book and from the events it wrestles with. There is also much to be learned from the fact that is was a collaborative effort between a Christian and a Jew. They have dedicated their book to their wives, who sustained them in their struggle to write it, as "a post-Holocaust sign that Christians and Jews can be brothers and sisters who care very much for one another" (page ix).

Chaplain (Major) W. Gregg Monroe
USA

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